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Smith, AN

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# Eye Movement Desensitisation and Reprocessing Therapy for People with Intellectual Disability in the Treatment of Emotional Trauma and Post Traumatic Stress Disorder: A Scoping Review

Alexander Nicholas Smith<sup>a</sup>, Richard Laugharne<sup>b,c</sup>, Katy Oak<sup>d</sup>, and Rohit Shankar<sup>b,c</sup> 

<sup>a</sup>University of Exeter Medical School, Truro, UK; <sup>b</sup>Cornwall Partnership NHS Foundation Trust, Bodmin, Cornwall, UK; <sup>c</sup>Cornwall Health Library Knowledge Spa, Royal Cornwall Hospital, Truro, UK; <sup>d</sup>University of Plymouth Medical School – Cornwall Intellectual Disability Research (CIDR), Truro, UK

## ABSTRACT

**Introduction:** Individuals with intellectual disability (ID) are at significant risk of developing emotional trauma and post-traumatic stress disorder (PTSD) due to altered neuropsychological functioning, increased chance of experiencing adverse life events, difficulty expressing emotions, diagnostic overshadowing and institutional failures. Eye Movement Desensitization and Reprocessing Therapy (EMDR) is efficacious in the general population, but research lacks evidence to suggest EMDR remains effective in ID. This paper assesses the evidence available on the use of EMDR to treat PTSD in ID and provide direction for future research.

**Methods:** A scoping review using PRISMA guidance was conducted. PsychInfo, Embase and Medline were completed using the NICE Health Databases Advanced Search in March 2020. Supplementary searches of Joanna Briggs and ongoing randomized controlled trials were also conducted. The terms used related to Intellectual disability and EMDR therapy. Searches were conducted without the use of PTSD or trauma-related terms to increase the number of identified articles. Inclusion criteria involved the use of EMDR therapy as the primary intervention using a population of individuals with ID. Only articles available in English were included. There were no exclusions related to the study design. All study designs and publication types were included in this review to capture the breadth of information that might be available on the topic. Articles identified were summarized, appraised and collated into tables. Papers were assessed for quality using the GRADE criteria.

**Results:** Out of 16 identified publications, 13 demonstrated positive results and 3 less favorable. Heterogeneity among participants, variations in EMDR protocol/adaptations, and variation in trauma and PTSD assessment were prevalent.

**Conclusions:** It is not possible to conclude whether EMDR is efficacious in people with ID. Future studies need to use homogenized populations, standardized EMDR protocol and validated trauma and PTSD assessments.

## KEYWORDS

EMDR; PTSD; intellectual disability; trauma

## INTRODUCTION

Individuals with intellectual disability (ID) face greater challenges than others when processing difficult experiences. Individuals with ID are known to have altered neuropsychological functioning and dysfunction in stress response, systems known to play a key role in the pathophysiology of posttraumatic stress disorder (PTSD) (Bomyea et al., 2012). Individuals with ID are also at higher risk of experiencing traumatic experiences in their lifetimes (Wigham & Emerson, 2015). This is a result of being more likely to encounter environmental stressors such as poverty, interpersonal violence as a child, carer-inflicted violence in supportive care settings, disruption of residence, bullying and discrimination (Emerson & Hatton, 2007; Reiter et al., 2007). Individuals with ID may also experience difficulty in expressing emotions, meaning that prevalence of emotional trauma in this population is often underreported and difficult to assess (Kildahl et al., 2019; Rittmannsberger et al., 2019; Wigham & Emerson, 2015). Diagnostic overshadowing also remains problematic for people with ID, leading to the referral of these individuals toward behavioral-based rather than trauma-based therapies, due to the lack of identification of trauma as the cause of their symptoms (Barol & Seubert, 2010; Mitchell & Clegg, 2005). By labeling the crux of the patient's difficulties as a by-product of ID rather than trauma, another barrier is created in the pursuit of accessing the most appropriate therapy. Furthermore, the historic institutional failure to provide adequate funding to ID services, coupled with insufficient training of mental health professionals and poor coordination across service sectors creates yet another hurdle for people with ID to access treatment (Whittle et al., 2018).

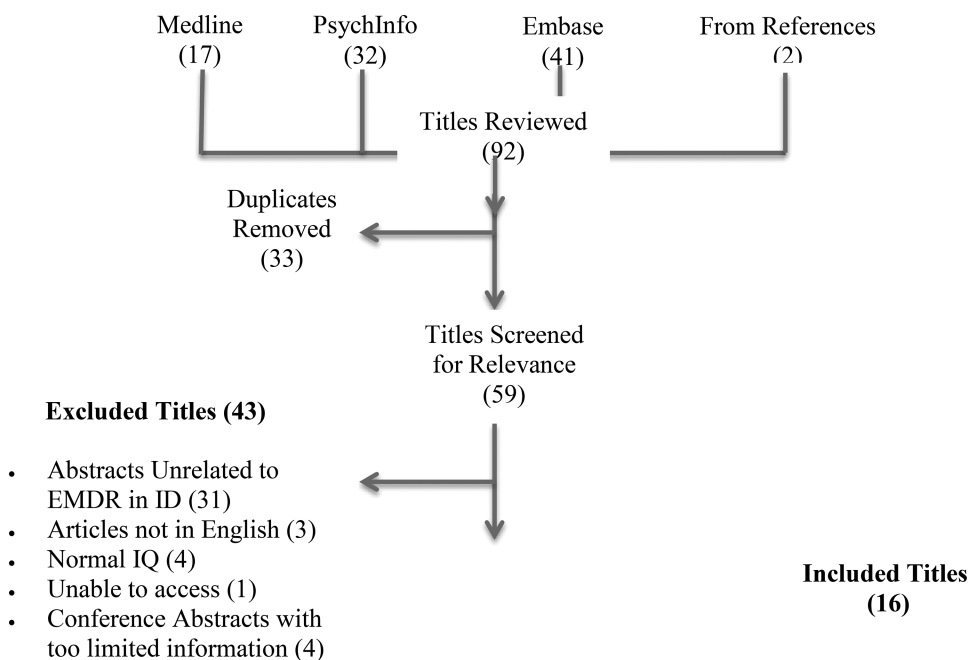
The combination of the aforementioned issues, in conjunction with an innate ableist societal attitude, creates a vulnerable situation for individuals with ID, making it likely that emotional trauma and PTSD are over-represented and poorly treated in this population.

According to the National Institute of Health and Care Excellence (NICE) guidelines, eye movement desensitization reprocessing (EMDR) is indicated in the treatment of PTSD (National Institute for Health and Care Excellence [NICE], 2018). Please refer to [Appendix A](#) for a summary EMDR therapy. NICE recommends the use of EMDR in adults with a diagnosis of PTSD or symptoms of PTSD who have presented between 1 and 3 months after a non-combat-related trauma, guidelines based on Cochrane evidence (Bisson et al., 2013; NICE, 2018). Systematic reviews in the general population also indicate the use of EMDR therapy in the treatment of psychotic or affective symptoms, and as an adjunct in chronic pain patients (Valiente-Gómez et al., 2017). This evidence points to an effective treatment in individuals without ID, but NICE guidelines do not state whether EMDR is effective in individuals with ID. EMDR requires reasonable communication and cognitive processing from the

participant. Neither of these are presumed to be granted in people with ID. Given that people with ID are prone to develop emotional trauma and PTSD, and are predisposed to cognitive and communication impairments, it is crucial for clinicians to identify the nature and type of research done to date on the effectiveness of EMDR for people with ID. By doing this through a scoping review approach, the breadth of available information can be assessed to identify gaps in current knowledge to better determine the best direction for future research. The aim of this review is to evaluate the use of EMDR in individuals with ID suffering with emotional trauma or PTSD in currently available literature.

## MATERIALS AND METHODS

This scoping review was conducted using PRISMA guidance (Tricco et al., 2018). A literature search of PsychInfo, Embase and Medline was completed using the NICE Health Databases Advanced Search. Supplementary searches of Joanna Briggs and ongoing randomized controlled trials (RCTs) were also conducted. The terms used related to Intellectual disability and EMDR therapy. Searches were conducted without the use of PTSD or trauma-related terms to increase the number of identified articles. A full list of search terms is provided in [Appendix B](#) and a flow chart highlighting the literature screening process is shown in [Figure 1](#).



**Figure 1.** Flow chart to illustrate literature exclusion process.

Initial identification of relevant articles was undertaken, followed by abstract screening and assessment for suitability. Included articles involved the use of EMDR therapy as the primary intervention using a population of individuals with ID. Only articles available in English were included. All study designs and publication types were included in this review to capture the breadth of information that might be available on the topic. For the same reason no date range was used. The most recent search was executed on 6th March 2020.

Articles were described using predetermined categories arranged in table format. Table 1 summarizes details regarding the included participants, PTSD/ID diagnosis and EMDR process described in the identified literature.

Table 2 summarizes details regarding the findings, bias and limitations, conclusions, Oxford Center for Evidence-based Medicine – Levels of Evidence (GRADE) score and the author's general comments on the identified literature.

Table 3 was created separately from the other two tables and only includes studies of literature review design. This is because the predetermined categories used to assess the literature were different. These categories were method, results, discussion, limitations and conclusions, and the authors' general comments.

In all tables, the paper details are included in the first column to help identify the paper. Each article was assigned a GRADE score to help evaluate the quality of evidence (Philips et al., 2009). Outcomes were at times reported in a unique way for table row entries. It was difficult to standardize a reporting method due to the wide variety of outcome measures used in each study, but every effort was made to standardize reporting between studies with a similar design.

## RESULTS

Ninety-two articles were identified from PsychInfo, Embase, Medline and the references section of literature found in the search. No articles were found by supplementary search. Thirty-three articles were removed as they were duplicates. Fifty-nine articles were screened for relevance with 43 titles excluded. Thirty-one articles were unrelated to EMDR use in people with ID. Three articles were unavailable in English. Four articles were excluded as they only included individuals without ID. Four conference abstracts were excluded as too little information was available to draw valuable conclusions. One PhD thesis was excluded due to lack of access. In total, 16 articles were analyzed after exclusion. Of the 16 articles there were four case series, three case reports, three literature reviews, two book chapters using the author's patients as part of their discussion, two multiple baselines across participants studies (one of

Table 1. Summary of participant profiles, PTSD and ID diagnosis and EMDR process for each relevant identified piece of literature.

Paper details:		Participant profile:		PTSD and ID diagnosis:		EMDR process:	
<b>Title:</b> A mixed-methods randomized control feasibility trial of Eye Movement Desensitization and Reprocessing (EMDR) plus Standard Care (SC) versus SC alone for DSM-5 Posttraumatic Stress Disorder (PTSD) in adults with intellectual disabilities		<b>Demographics:</b> Total Number of Participants (n = 29) <b>EMDR+SC (n = 15)</b> – Mean age 42, SD = 11.3, 60% Female, 40% Male, <b>SC Only (n = 14)</b> – Mean age 42, SD = 12.1, 64.3% Female, 35.7% Male <b>ID Characteristics:</b> <b>Severity:</b> Mild-moderate ID <b>EMDR+SC</b> – 13 Mild, 2 Moderate <b>SC Only</b> – 11 Mild, 3 Moderate <b>Neurodevelopmental or Autism:</b> Not reported <b>Verbal/non-verbal:</b> Not reported <b>Comorbidities:</b> <b>EMDR+SC</b> – 12 with comorbidity, 3 without <b>SC Only</b> – 7 with comorbidity, 7 without <b>Medications:</b> <b>EMDR+SC</b> – 13 taking psychotropics, 2 not taking <b>SC Only</b> – 12 taking psychotropics, 2 not taking		<b>Data Collection:</b> Data sourced from case notes, clinical interviews and participant self-reporting. <b>Responsible Person for PTSD/ID</b> <b>Diagnosis:</b> Unclear who made ID diagnosis, but all patients were recruited from NHS outpatients ID services clinics. PTSD assessments made by research assistant with member of the research team present. <b>Criteria used to Diagnose PTSD/ID:</b> Unclear criteria for ID diagnosis apart from use of mild/moderate terminology. Presence of adult and childhood trauma assessed using Life Events Checklist (LEC) and Childhood Trauma Questionnaire (CTQ) (Bernstein & Fink, 1998; Gray et al., 2004). PTSD diagnosed using PCL-5 and were excluded if <38 (score 38 or more gives DSM-5 diagnosis of PTSD) (Weathers et al., 2013).		<b>EMDR Protocol:</b> Shapiro Adult EMDR protocol (Shapiro, 2001) <b>Time Period:</b> Recruitment between Jan 2014 and December 2016. Unclear over how long sessions took place for each participant. <b>Number and Length of EMDR Sessions:</b> Up to 8 sessions offered lasting up to 1 hour. 12 participants attended 4 or more of the 8 EMDR sessions. The mean number of sessions was 3.1, standard deviation was 2.15. <b>Who performed intervention:</b> Administered by two psychiatrists, one clinical psychologist and one social worker all trained to deliver EMDR to adults with ID. <b>Ethical Considerations:</b> Consent gained with participants excluded if unable or unwilling to give consent	

(Continued)

Table 1. (Continued).

Paper details:		Participant profile:	PTSD and ID diagnosis:	EMDR process:
<b>Title:</b> Eye movement desensitization and reprocessing for adults with intellectual disabilities: Process issues from an acceptability study		<b>Demographics:</b> Total Number of Participants (n = 3) <b>Participants</b> – 3 females, C01, C02 and C03, aged 23, 40–50 and 42 respectively <b>ID Characteristics:</b> <b>ID Severity</b> – 2 participants with Mild-moderate and 1 with Borderline-mild reported <b>Neurodevelopmental or Autism:</b> – Not reported <b>Verbal/non-verbal</b> – Not reported <b>Comorbidities:</b> Not reported <b>Medications:</b> Not reported	<b>Data collection:</b> Interviews with patients and patient hospital notes <b>Responsible Person for PTSD/ID</b> <b>Diagnosis:</b> Not reported <b>Criteria used to diagnose PTSD/ID:</b> Not reported	<b>EMDR Protocol:</b> Shapiro Adult EMDR Protocol adapted by the therapist to suit the needs of participants (Shapiro, 2017). <b>C01</b> – Tactile and auditory BLS <b>C03</b> – Eye movements BLS <b>C03</b> – Tactile BLS <b>Time period:</b> <b>C01</b> – 12 months <b>C02</b> – 13 months <b>C03</b> – Not reported <b>Number and length of EMDR Sessions:</b> Not reported <b>Who performed intervention:</b> Three experienced specialist intellectual disabilities clinical psychologists received 3 or 4 part accredited training in EMDR adult protocol, none had previous experience of using EMDR. <b>Ethical Considerations:</b> Consent gained for all participants with only those with capacity to consent included in the study

(Continued)

Table 1. (Continued).

Paper details:		Participant profile:		PTSD and ID diagnosis:		EMDR process:	
<b>Title:</b> Eye Movement desensitization and reprocessing therapy for posttraumatic stress disorder in a child and an adolescent with mild to borderline intellectual disability: A multiple baseline across subjects study		<b>Demographics:</b> Total Number of Participants (n = 2) <b>William</b> – 10-year-old male <b>Rose</b> – 18-year-old female <b>ID Characteristics:</b> <b>Severity:</b> Both mild to borderline <b>William</b> – IQ of 66 <b>Rose</b> – IQ of 67 <b>Neurodevelopmental or Autism</b> – Neurodevelopmental (Participants excluded if autism was diagnosed) <b>Verbal/non-verbal</b> – Not reported <b>Comorbidities:</b> Not reported <b>Drugs:</b> Not reported		<b>Data collection:</b> Video recordings of patient interviews and case notes <b>Responsible Person for PTSD/ID Diagnosis:</b> PTSD Diagnosis made by trained psychologist. Not reported who diagnosed ID. <b>Criteria used to diagnose PTSD/ID:</b> DSM-IV and DSM-V PTSD criteria met using a reliable PTSD diagnosis tool in ID called Adapted ADIS-C PTSD (Mevissen et al., 2014, 2016). Not reported how ID was diagnosed.		<b>EMDR Protocol:</b> Dutch protocol for children and adolescents (De Roos et al., 2012). Eye movement BLS given as standard for the protocol. The use of VOC was omitted in William's treatment due to lack of understanding. <b>Time period:</b> Not reported <b>Number and length of EMDR Sessions:</b> 4 x 60-minute sessions <b>Who performed intervention:</b> EMDR performed by a licensed clinical psychologist and EMDR Europe-accredited consultant, and psychologist trained in EMDR at advanced level, supervised by the licensed clinical psychologist. <b>Ethical Considerations:</b> Written consent given from all participants	

(Continued)



Table 1. (Continued).

Paper details:		Participant profile:	PTSD and ID diagnosis:	EMDR process:
<b>Title:</b>	Eye Movement Desensitization and Reprocessing with Adults with Intellectual Disability	<b>Demographics:</b> Total Number of Participants (n = 6) <b>050:</b> 37 y/o Female <b>051:</b> 69 y/o Male <b>052:</b> 53 y/o Female <b>053:</b> 48 y/o Female <b>066:</b> 62 y/o Male <b>068:</b> 41 y/o Male	<b>Data collection:</b> Case notes and clinical interviews <b>Responsible Person for PTSD/ID Diagnosis:</b> Dr Harvey, the associative executive director of quality supports, a clinician experienced with the use of EMDR and working with individuals with ID <b>Criteria used to diagnose PTSD/ID:</b> DSM-IV-TR for two diagnostic categories, IES-R, C-PTSD-I; DM-ID (IQ 55–75) using the Wechsler abbreviated scale of intelligence (American Psychiatric Association [APA], 2000; Fletcher et al., 2007; Horowitz et al., 1979; Saigh, 2004; Wechsler, 1999)	<b>EMDR Protocol:</b> Shapiro, 2001 adult protocol with appropriate changes made to language so that the client was able to understand (Shapiro, 2001). Scripts used where possible to minimize variation in delivery. All participants used eye movement BLS. <b>Time Period:</b> <b>050:</b> 60 visits <b>052:</b> 69 visits <b>053:</b> 96 visits <b>051:</b> 65 visits <b>066:</b> 80 visits <b>068:</b> 73 visits Visit number refers to total number of visits throughout the protocol period <b>Number and length of EMDR Sessions:</b> Maximum length of time in intervention stage was 18 weeks. Length and number of sessions was not reported. <b>Who performed intervention:</b> Principal investigator, the author of this study Lynn Buhler who is a clinical psychologist <b>Ethical Considerations:</b> Participants included only if deemed capable of providing informed consent by a qualified representative of the Developmental Disabilities Administration.
<b>Year:</b>	2014			
<b>Country:</b>	USA (Florida)			
<b>Type:</b>	PhD Dissertation (Multiple Baseline Across Participants with A-B-A Follow up Design)	<b>ID Characteristics:</b> <b>Severity:</b> All Mild ID (IQ 55–75) <b>050:</b> FSIQ = 64 <b>051:</b> FSIQ = 66 <b>052:</b> FSIQ = 71 <b>053:</b> FSIQ = 66 <b>066:</b> FSIQ = 68 <b>068:</b> FSIQ = 58		
<b>Author:</b>	(Buhler, 2014)	<b>Neurodevelopmental or Autism:</b> All Neurodevelopmental (Participants excluded if autism was diagnosed) <b>Verbal/non-verbal:</b> Verbal IQ (VIQ) scores gathered from participants <b>050:</b> VIQ = 55 <b>051:</b> VIQ = 57 <b>052:</b> VIQ = 71 <b>053:</b> VIQ = 66 <b>066:</b> VIQ = 60 <b>068:</b> VIQ = 55		
		<b>Comorbidities:</b> <b>050:</b> Dissociative Disorder (NOS) <b>051:</b> None <b>052:</b> Major Depression <b>053:</b> None <b>066:</b> Major Depression <b>068:</b> Psychotic Disorder (NOS) <b>Medications:</b> <b>050:</b> Prozac <b>051:</b> None <b>052:</b> Trazadone, Paxil <b>053:</b> None <b>066:</b> Lexapro, Seroquel, Trazadone <b>068:</b> Zyprexa, Depakote		

(Continued)

Table 1. (Continued).

Paper details:		Participant profile:	PTSD and ID diagnosis:	EMDR process:
<u>Title:</u>		<u>Demographics:</u>	<u>Data Collection:</u>	<u>EMDR Protocol:</u>
Stepping Stones: EMDR Treatment of Individuals With Intellectual and Developmental Disabilities and Challenging Behavior		Total Number of Participants (n = 6) <b>Teresa:</b> 31-year-old Female <b>James:</b> 28-year-old Male <b>Tom:</b> 20-year-old Male <b>Kate:</b> 28-year-old Female <b>Mark:</b> 22-year-old Male <b>Antony:</b> 40-year-old Male	Case notes and clinical interviews <b>Responsible Person for PTSD/ID Diagnosis:</b> Not reported <b>Criteria used to diagnose PTSD/ID:</b> ID criteria unclear. Integrated bespoke assessment tool was created based on DSM-IV 19 symptom checklist, 59 item psychiatric questionnaire, Sovner, 1993 adaptive checklist of psychiatric symptoms and generic 32 item list of indicators of PTSD in ID population (APA, 1994; Sovner, 1993)	hapiro adult protocol used with individual client modifications (Shapiro, 2001). Full protocol used with Teresa and James. Greater time was invested in the preparation phase with all clients in order to develop therapeutic rapport. More frequent SUD checking and fragmenting of memories into smaller more manageable parts was done. The therapist was more verbally involved than in standard protocol to keep participants concentrated. Visual representations and language adaptations of VOC and SUD used to aid understanding. With some participants, the Lovett storytelling method was employed (Lovett, 1999).
<b>Country:</b> USA		<b>ID Characteristics:</b> <b>Severity:</b> mild-severe ID <b>Teresa:</b> IDD mild range <b>James:</b> IDD mild range <b>Tom:</b> IDD moderate range <b>Kate:</b> IDD severe range <b>Mark:</b> IDD mild range <b>Antony:</b> IDD moderate-mild range		<b>Teresa:</b> Electronic tactile and auditory BLS <b>James:</b> Eye movement BLS <b>Tom:</b> Tapping tactile BLS <b>Kate:</b> Tapping on knees tactile BLS <b>Mark:</b> Not reported <b>Antony:</b> Auditory and tactile BLS
<b>Type:</b> Case Series		<b>Neurodevelopmental or Autism:</b> <b>Teresa:</b> Autism <b>James:</b> Neurodevelopmental <b>Tom:</b> Autism <b>Kate:</b> Autism <b>Mark:</b> Autism <b>Antony:</b> Cerebral Palsy		<b>Time period:</b> <b>Teresa:</b> 8 months <b>James:</b> 8 months <b>Tom:</b> Not reported <b>Kate:</b> 4 months <b>Mark:</b> 8 months <b>Antony:</b> Not reported
<b>Author:</b> (Barol & Seubert, 2010)		<b>Verbal/non-verbal:</b> <b>Teresa:</b> Verbal <b>James:</b> Verbal <b>Tom:</b> Minimally articulate <b>Kate:</b> Not articulate and not able to verbally reflect feelings <b>Mark:</b> Verbal <b>Antony:</b> Verbal		<b>Number and length of EMDR Sessions:</b> <b>Teresa:</b> 10 × 1 hour <b>James:</b> 12 × 2 hour <b>Tom:</b> 9 sessions of unknown length <b>Kate:</b> Not reported <b>Mark:</b> semimonthly sessions of unknown quantity and length <b>Antony:</b> Not reported
		<b>Comorbidities:</b> <b>Teresa:</b> Anxiety Disorder <b>James:</b> Tourette's and bipolar <b>Kate:</b> Bipolar <b>Mark:</b> Bipolar <b>Antony:</b> Mild cerebral palsy and bipolar		<b>Who performed intervention:</b> Unclear in all cases
		<b>Medications:</b> Not reported		<b>Ethical Considerations:</b> Each of the participants consented to be part of the study

(Continued)

Table 1. (Continued).

Paper details:		Participant profile:	PTSD and ID diagnosis:	EMDR process:
<b>Title:</b> EMDR Treatment in People with Mild ID and PTSD: 4 Cases		<b>Demographics:</b> Total Number of Participants (n = 4) <b>John:</b> 32-year-old Male <b>Mitchell:</b> 11-year-old Male <b>Mary:</b> 53-year-old Female <b>Eve:</b> 7-year-old Female	<b>Data Collection:</b> Client records and videotaping of clinical interview to determine appropriateness for treatment and record findings. <b>Responsible Person for PTSD/ID</b> <b>Diagnosis:</b> Not reported who made official diagnosis but person performing the EMDR assessed PTSD and ID symptoms for suitability for study. <b>Criteria used to diagnose PTSD/ID:</b> WISC-R, SRZ-P, DSM-IV-TR and DM-ID (APA, 2000; Fletcher et al., 2007; Kraijer & Kema, 2004; Wechsler, 1999)	<b>EMDR Protocol:</b> Dutch translation of Shapiro's 2001 protocol with adaptation to client's level of cognitive and emotional functioning (Shapiro, 2001) (De Jongh & Ten Broeke, 2003). <b>John:</b> Auditory BLS used. Client able to mentally visualize and verbalize thoughts. Child Protocol used. <b>Mitchell:</b> Auditory (headphones) and tactile (buzzer) BLS used. Child protocol used. <b>Mary:</b> Headphones for auditory BLS. Child protocol used. <b>Eve:</b> Tactile BLS using buzzers. Poor concentration and reluctance to follow instructions leading to use of Lovett story telling method (Lovett, 1999). <b>Number and length of EMDR Sessions:</b> Weekly sessions of up to 60-minutes given according to client need. <b>John:</b> 2 sessions <b>Mitchell:</b> 5 sessions <b>Mary:</b> 13 sessions <b>Eve:</b> 3 sessions <b>Who performed intervention:</b> Clinical psychologist and registered EMDR practitioner with more than 30 years of experience of clients with ID. <b>Ethical Considerations:</b> All sessions were videotaped with written consent of the client or caretaker.
<b>Year:</b> 2011				
<b>Country:</b> Netherlands				
<b>Type:</b> Case Series				
<b>Author:</b> (Mevisen et al., 2011a)				
		<b>Verbal/non-verbal:</b> All verbal, Verbal IQ (VIQ) scores measured using WISC-R <b>John:</b> VIQ = 70 <b>Mitchell:</b> VIQ = 72 <b>Mary:</b> VIQ = 49 <b>Eve:</b> VIQ = 82 <b>Comorbidities:</b> <b>John:</b> Unknown <b>Mitchell:</b> Diagnosis of MCDD which no longer applied post treatment <b>Mary:</b> Anxiety <b>Eve:</b> Autism Spectrum disorder diagnosis <b>Drugs:</b> <b>John:</b> Not reported <b>Mitchell:</b> Pipamperon <b>Mary:</b> SSRI <b>Eve:</b> No Psychotropic		

(Continued)

Table 1. (Continued).

Paper details:		Participant profile:		PTSD and ID diagnosis:		EMDR process:	
<b>Title:</b> Do persons with intellectual disability and limited verbal capacities respond to trauma treatment?	<b>Demographics:</b> Total Number of Participants (n = 2) <b>Maria:</b> Young Female <b>Simon:</b> Middle-aged Male <b>ID Characteristics:</b> <b>Severity</b> Moderate <b>Maria:</b> Moderate, IQ = 44 on WISC-R <b>Simon:</b> Moderate, average age of development was 4.9 years on WPPSI-R <b>Neurodevelopmental or Autism:</b> <b>Maria:</b> Not reported (possesses symptoms of autism but not diagnosed) <b>Simon:</b> Neurodevelopmental <b>Verbal/non-verbal:</b> Substantially limited verbal capacities in both <b>Comorbidities:</b> <b>Maria:</b> Not reported <b>Simon:</b> Not reported <b>Drugs:</b> <b>Maria:</b> Risperidone <b>Simon:</b> Not reported	<b>Data Collection:</b> Clinical interviews with participants and trusted care givers, record examination. Videotaping of interviews. Therapist analyzed videotapes with focus on significant aspects of trauma processing. <b>Responsible Person for PTSD/ID Diagnosis:</b> Clinical psychologist/EMDR practitioner with more than 30 years experience with people with ID and mental health <b>Criteria used to diagnose PTSD/ID:</b> Not clear whether diagnosis given but participants screened for symptoms of PTSD-like symptoms and ID criteria using DSM-IV-TR and DM-ID (APA, 2000; Fletcher et al., 2007). WISC-R and WPPSI-R used for ID diagnosis.	<b>EMDR Protocol:</b> Shapiro, 2001 protocol with individual modification (Shapiro, 2001). <b>Maria:</b> Auditory BLS given using speakers due to intolerance of headphones, buzzers and eye movements. Client unable to verbalize or create drawings, so Lovett story telling method used (Lovett, 1999). <b>Simon:</b> Tactile BLS used in form of Buzzers. Client unable to verbalize or draw so Lovett story telling method used. <b>Time period:</b> One session per week until patient felt therapy was no longer necessary <b>Number and length of EMDR Sessions:</b> <b>Maria:</b> 6 × 1 hour <b>Simon:</b> 5 × 1 hour <b>Who performed intervention:</b> A Clinical psychologist/EMDR practitioner with more than 30 years experience with people with ID and mental health <b>Ethical Considerations:</b> Written informed consent was obtained from all clients who agreed to participate after the procedures were explained.				

(Continued)

Table 1. (Continued).

Paper details:		Participant profile:		PTSD and ID diagnosis:		EMDR process:	
<b>Title:</b> Treatment of PTSD in people with severe intellectual disabilities: A case series <b>Year:</b> 2012 <b>Country:</b> Netherlands <b>Type:</b> Case Series <b>Authors:</b> (Mevisen et al., 2012)		<b>Demographics:</b> Total Number of Participants (n = 4) <b>Jane:</b> 49-year-old Female <b>Melissa:</b> 10-year-old Female <b>Peter:</b> 10-year-old Male <b>Joany:</b> 32-year-old Female <b>ID Characteristics:</b> <b>Severity:</b> All severe <b>Neurodevelopmental or Autism:</b> <b>Jane:</b> Down's Syndrome <b>Melissa:</b> Marshal Smith Syndrome <b>Peter:</b> Down's Syndrome <b>Joany:</b> Autism Symptoms <b>Verbal/non-verbal:</b> Not reported <b>Comorbidities:</b> <b>Jane:</b> Down's Syndrome <b>Melissa:</b> Marshal Smith Syndrome <b>Peter:</b> History of cardiac disease requiring surgery and Down's syndrome <b>Joany:</b> Not reported <b>Medications:</b> <b>Jane:</b> Pain medication <b>Melissa:</b> Not reported <b>Peter:</b> Not reported <b>Joany:</b> Antipsychotics (given temporarily without good effect)		<b>Data Collection:</b> Client case records and video recordings <b>Responsible Person for PTSD/ID Diagnosis:</b> Unclear but either a psychologist or psychiatrist <b>Criteria used to diagnose PTSD/ID:</b> DSM-IV TR for PTSD and DM-ID for ID (APA, 2000; Fletcher et al., 2007).		<b>EMDR Protocol:</b> Shapiro, 2001 adult protocol with age-related and mental age adaptations (Shapiro, 2001). Distress measured using visual cues, for example, facial images or hand spreading (Adler-Tapia & Settle, 2008; Greenwald, 1999). EMDR story telling method also employed (Lovett, 1999). Vivid recollection of disturbing memories enhanced with aid of drawings, objects, noises, smells and physical sensations. <b>Jane:</b> Tactile BLS using alternating buzzers in left and right hand <b>Melissa:</b> Unable to tolerate physical, sensory or visual BLS, so was given auditory <b>Peter:</b> Buzzers trialed but rejected due to association with negative emotions. Knee tapping and audio speakers accepted as BLS before tolerating buzzers by 3 <sup>rd</sup> session <b>Joany:</b> Auditory BLS <b>Time period:</b> EMDR offered based on client's individual needs (therapy terminated when client felt it was no longer necessary). <b>Number and length of EMDR Sessions:</b> 60 minute sessions for all participants <b>Jane:</b> 7 <b>Melissa:</b> 14 <b>Peter:</b> 3 <b>Joany:</b> 17 <b>Who performed intervention:</b> All EMDR performed by one clinical psychologist with 30+ years experience with ID patients <b>Ethical Considerations:</b> Information about treatment and related procedures were explained in detail to the caregivers, who were also given printed treatment information to be read at home. The legal guardians of all four clients agreed to EMDR treatment for their wards and to their participation in the present study and signed an informed consent form.	

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Table 1. (Continued).

Paper details:		Participant profile:	PTSD and ID diagnosis:	EMDR process:
<b>Title:</b> Eye movement desensitization and reprocessing in an adolescent with epilepsy and mild intellectual disability <b>Year:</b> 2009 <b>Country:</b> Netherlands <b>Type:</b> Case Report <b>Authors:</b> (Rodenburg et al., 2009)	<b>Demographics:</b> Total number of participants (n = 1) <b>Tom:</b> 18-year-old Male <b>ID Characteristics:</b> <b>Severity:</b> Mild <b>Tom:</b> Total IQ = 67–77, Performance IQ 67–81 on WAIS III-NL <b>Neurodevelopmental or Autism:</b> Neurodevelopmental <b>Verbal/non-verbal:</b> Not reported <b>Comorbidities:</b> Cryptogenic epilepsy with pharmacoresistant tonic-clonic seizures <b>Medication:</b> Sodium Valproate, lamotrigine, levetiracetam	<b>Data Collection:</b> Case notes <b>Responsible Person for PTSD/ID Diagnosis:</b> Not reported <b>Criteria used to diagnose PTSD/ID:</b> PTSD diagnosed using a Dutch version of the Impact Event Scale (IES) (Brom & Kleber, 1985). WAIS-III-NL used to diagnose ID (Wechsler, 2001) .	<b>EMDR Protocol:</b> Adapted children's EMDR protocol with age-appropriate modifications (Beer & De Roos, 2004). <b>Time period:</b> Not reported <b>Number and length of EMDR Sessions:</b> 5 sessions lasting 45 minutes to 1 hour <b>Who performed intervention:</b> Psychologist with specialism in children's EMDR therapy <b>Ethical Considerations:</b> No mention of participant consent or caregiver consent in this publication	

(Continued)

Table 1. (Continued).

Paper details:		Participant profile:		PTSD and ID diagnosis:		EMDR process:	
<u>Title:</u>		<u>Demographics:</u>		<u>Data Collection:</u> Review of clinical case files		<u>EMDR Protocol:</u>	
Eye movement Desensitization and Reprocessing in the treatment of trauma with mild intellectual disability: a case study		Total Number of Participants (n = 1) <b>Simon:</b> 25-year-old Male		<b>Responsible Person for PTSD/ID Diagnosis:</b> Not reported		Shapiro protocol (Shapiro, 2001).	
<b>Year:</b> 2014		<b>ID Characteristics:</b> <b>Severity:</b> Mild		<b>Criteria used to diagnose PTSD/ID:</b> WAIS-IV 2008 for use to aid ID diagnosis (Wechsler, 2008). Posttraumatic Diagnostic Scale (PDS) used to aid diagnosis of PTSD based on DSM-IV criteria (Foa et al., 1997).		<b>Time period:</b> Not reported	
<b>Country:</b> UK		<b>Simon:</b> WAIS-IV score was in extremely low range		<b>Who performed intervention:</b> Trauma therapist		<b>Number and length of EMDR Sessions:</b> 12 sessions of unknown length	
<b>Type:</b> Case Report		<b>Neurodevelopmental or Autism:</b> Neurodevelopment		<b>Ethical Considerations:</b> Consent was gained from the responsible clinician and patient for this anonymized case study.			
<b>Author:</b> (Dilly, 2014)		<b>Verbal/non-verbal:</b> Verbal but limited receptive vocabulary and understanding of grammatical structures is poor. Significant impairment in expressive vocabulary, in particular to express feelings and emotions.					
		<b>Comorbidities:</b> Not reported					
		<b>Medication:</b> Not reported					

(Continued)

Table 1. (Continued).

Paper details:		Participant profile:		PTSD and ID diagnosis:		EMDR process:	
<b>Title:</b> EMDR treatment for PTSD and intellectual disability: a case study		<b>Demographics:</b> Total Number of Participants (n = 1) <b>Ethel:</b> 40-year-old Female		<b>Data Collection:</b> Case Notes		<b>EMDR Protocol:</b> Shapiro, 2001 protocol used with adaptations to suit Ethel's level of ID (Shapiro, 2001). Use of structured fixed narrative of short length rather than more lengthy recounting. Visual inspection of body language and facial expression used to measure distress level rather than SUD or VOC scales. Eye movement not possible due to blindness. Tactile BLS used in the form of hand tapping instead.	
<b>Year:</b> 2015		<b>ID Characteristics:</b> <b>Severity:</b> Moderate-severe		<b>Diagnosis:</b> Not reported			
<b>Country:</b> UK		<b>Neurodevelopmental or Autism:</b> Neurodevelopmental		<b>Criteria used to diagnose PTSD/ID:</b> Language complexity of PTSD rating scales was too high, therefore symptom presentation benchmarked against DSM-IV-TR criteria using modification proposed by Tomasulo and Razza (Fletcher et al., 2007). CRIES-13, a children's version of IES corroborated with third party information on Ethel helped to diagnose PTSD (Perrin et al., 2005).			
<b>Type:</b> Case Report		<b>Verbal/non-verbal:</b> Limited verbal capacity				<b>Time period:</b> Not reported	
<b>Authors:</b> (Barrowcliff & Evans, 2015)		<b>Comorbidities:</b> Mucopolysaccharidosis Hunters Syndrome (blindness in adulthood associated with the condition)				<b>Number and length of EMDR Sessions:</b> 4 sessions of unknown length	
		<b>Medication:</b> Not reported				<b>Who performed intervention:</b> Not reported	
				<b>Not reported how ID was diagnosed.</b>		<b>Ethical Considerations:</b> No mention of participant consent or caregiver consent in this publication	

(Continued)



Table 1. (Continued).

Paper details:		Participant profile:		PTSD and ID diagnosis:		EMDR process:	
<b>Title:</b> Left Out and Left Behind: EMDR and the Cultural Construction of Intellectual Disability <b>Year:</b> 2017 <b>Country:</b> USA (NY) <b>Type:</b> Book Chapter containing 3 case studies <b>Authors:</b> (Yaskin & Seubert, 2017)	<b>Demographics:</b> Total Number of Participants (n = 3) <b>Mitchell:</b> 19-year-old Male <b>Jamie:</b> 35-year-old Female <b>Vanessa:</b> 25-year-old Female <b>ID Characteristics:</b> <b>Severity:</b> Not reported <b>Neurodevelopmental or Autism:</b> <b>Mitchell:</b> Neurodevelopmental (Down's Syndrome) <b>Jamie:</b> Not reported <b>Vanessa:</b> Not reported <b>Verbal/non-verbal:</b> Not reported <b>Comorbidities:</b> <b>Mitchell:</b> Down's Syndrome <b>Jamie:</b> Dissociative episodes Dissociative episodes <b>Vanessa:</b> Dissociative episodes <b>Medication:</b> Not reported		<b>Data Collection:</b> Case notes <b>Responsible Person for PTSD/ID Diagnosis:</b> Not reported <b>Criteria used to diagnose PTSD/ID:</b> Not reported		<b>EMDR Protocol:</b> Source of protocol not described. <b>Mitchell:</b> Use of hand spreading to measure VOC and SUD. BLS mostly through sound and vibration, sometimes eye movements. More frequent verbal interaction from therapist to help keep focus. Therapist didn't insist on establishing negative/positive cognitions due to reluctance to process event. Used pointing at images and resources to indicate how he felt. <b>Jamie:</b> Not reported <b>Vanessa:</b> Not reported <b>Time period:</b> Not reported <b>Number and length of EMDR Sessions:</b> <b>Mitchell:</b> 10–12 rounds of BLS <b>Jamie:</b> 2 rounds of BLS <b>Vanessa:</b> Not reported <b>Who performed intervention:</b> Andrew Seubert (Second Author) licensed psychotherapist and EMDR consultant administered therapy to Mitchell. Joseph Yaskin (First author) administered therapy to Jamie and Vanessa. <b>Ethical Considerations:</b> No mention of participant consent or caregiver consent in this publication		

(Continued)

Table 1. (Continued).

Paper details:		Participant profile:	PTSD and ID diagnosis:	EMDR process:
<b>Title:</b>	EMDR with Clients with mental Disability	<b>Demographics:</b>	<b>Data Collection:</b>	<b>EMDR Protocol:</b>
<b>Year:</b>	2005	Total Number of Participants (n = 2)	Case Notes	Shapiro protocol used (Shapiro, 2001).
<b>Country:</b>	USA (NY)	<b>Michael:</b> 17-year-old Male	<b>Responsible Person for PTSD/ID</b>	<b>Michael:</b> Mixture of auditory, visual and tactile BLS.
<b>Type:</b>	Book Chapter Using Details of Case Study	<b>ID Characteristics:</b>	<b>Diagnosis:</b>	<b>Carol:</b> Combination of eye movements and auditory BLS.
<b>Authors:</b>	(Seubert, 2005)	<b>Severity:</b> Mild-Moderate (IQ 50–70)	<b>Criteria used to diagnose PTSD/ID:</b>	<b>Time period:</b>
		<b>Michael:</b> Mild	PTSD diagnostic criteria not reported. ID diagnosed according to DSM-IV (APA, 1994).	Not reported
		<b>Carol:</b> Moderate		<b>Number and length of EMDR Sessions:</b>
		<b>Neurodevelopmental or Autism:</b>		Not reported
		<b>Michael:</b> Neurodevelopment (Down Syndrome)		<b>Who performed intervention:</b> Andrew Seubert, EMDR researcher and accredited practitioner
		<b>Carol:</b> Not reported		<b>Ethical Considerations:</b>
		<b>Verbal/non-verbal:</b>		No mention of participant consent or caregiver consent in this publication
		<b>Michael:</b> Verbal		
		<b>Carol:</b> Not reported		
		<b>Comorbidities:</b>		
		<b>Michael:</b> Hearing impairment		
		<b>Carol:</b> Not reported		
		<b>Drugs:</b>		
		Not Reported		

Table 2. Summary of findings, bias and limitations, GRADE score and the author's general comments for each relevant identified piece of literature.

Paper details		Findings	Bias and limitations	GRADE score and comments
<b>Title:</b> A mixed-methods randomized control feasibility trial of Eye Movement Desensitization and Reprocessing (EMDR) plus Standard Care (SC) versus SC alone for DSM-5 Posttraumatic Stress Disorder (PTSD) in adults with intellectual disabilities		<b>Improvement measures:</b> <b>Primary outcome</b> = PCL-5 score used to assess change in PTSD symptoms. Assessed by research assistant before treatment, one week post-treatment and at three months follow up. <b>Outcome:</b> <b>EMDR+SC</b> 9 participants diagnosis free at one week post treatment scoring <38 on the PCL-5 7 participants diagnosis free at three months follow up scoring <38 on the PCL-5 <b>SC Only</b> 4 participants diagnosis free at one week post treatment scoring <38 on the PCL-5 4 participants diagnosis free at three months follow up scoring <38 on the PCL-5 Changes in PCL-5 score between the two groups were not statistically significant. <b>Qualitative Findings</b> Seven participants took part in brief semi structured interviews post-therapy. Open ended questioning and a guided list of topics were used to discuss participation in the trial. The process of EMDR was found to be challenging at times, but overall found to be an acceptable intervention by participants. PTSD was reiterated to be a debilitating condition for participants. <b>Participant and Researcher Feedback</b> A dropout rate of 20% in the EMDR +SC group compared to SC alone with 7% was observed. This was validated in the discussion by confirming that EMDR and other psychological interventions in similar studies in the general population yielded similar dropout rates. Differences in dropout rates between groups for this study were not statistically significant. <b>Sub-Groups outcomes:</b> Not reported	<b>Reporting Bias Control:</b> <ul style="list-style-type: none"><li>● Random allocation into groups and blind assessments of participants by impartial research assistants</li><li>● Patients randomized into EMDR+SC (n = 15) and SC only (n = 14) groups</li><li>● <b>Limitations:</b><ul style="list-style-type: none"><li>● Small sample sizes mean inadequately powered study with high chance of type 2 error</li><li>● Lacked inclusion of another intervention to compare EMDR against</li><li>● Standard care comparator poorly defined stating that "all participants continued their usual psychological, psychiatric and medical care during the study"</li><li>● Standard care will have varied between participants complicating the evaluation of EMDR efficacy in this study</li><li>● Group samples contain a mixture of participants with mild and moderate ID, meaning differences in cognitive and communication abilities may have altered the efficacy of EMDR in certain participants</li><li>● Paucity of suitable and validated instruments to assess outcomes in people with ID</li><li>● Trauma assessment using IEC, CTQ and PCL-5 not tested in ID individuals</li><li>● Detailed information on whether psychotropic drugs were prescribed recently was not given which could have impacted the efficacy of EMDR</li><li>● Detailed information on comorbidities not given, which could have impacted the efficacy of EMDR</li><li>● Author does not report how ID severity was assessed</li><li>● Level of verbal communication and autism status not discussed, which could have impacted the efficacy of EMDR</li></ul></li></ul>	<b>GRADE score 2b</b> <ul style="list-style-type: none"><li>● First study to present less favorable results of EMDR therapy</li><li>● Only 12 participants attended 4 or more of the 8 sessions offered; raises question of how many EMDR sessions are required before symptom improvement</li><li>● Higher dropout rate in EMDR+SC group compared to SC Only group may suggest a level of intolerance to the therapy</li></ul>
<b>Year:</b> 2019				
<b>Country:</b> UK				
<b>Type:</b> Mixed Methods Randomized Control Trial				
<b>Citation:</b> (Karatzias et al., 2019)				

(Continued)

Table 2. (Continued).

Paper details		Findings	Bias and limitations	GRADE score and comments
<b>Title:</b> Eye movement desensitization and reprocessing for adults with intellectual disabilities: Process issues from an acceptability study <b>Year:</b> 2018 <b>Country:</b> UK <b>Type:</b> Qualitative Multiple Baseline Case Series <b>Citation:</b> (Unwin et al., 2019)		<b>Outcome:</b> <b>Themes</b> <b>EMDR feels very different:</b> Participants found elements of EMDR to be difficult, complex, and intrusive ultimately affecting engagement with therapy. Therapists worried that the client would not be able to adapt. <b>EMDR is a technical process:</b> Clients may have long-standing complex trauma not presenting with a single experience to use in desensitization and reprocessing. Clients may have difficulty understanding the complex mechanisms by which EMDR works, therefore lack of impetus to relieve. The psychologists administering EMDR did not feel confident in administering the therapy and struggled to adapt to a new approach. <b>The need to work with the present:</b> Individuals with ID may be prone to be more resistant to explore issues from the past, and therefore express preference to concentrate on current issues as this feels more relevant. <b>Talking is important:</b> Reduced focus on talking about present issues was less attractive to patients. The patients all had chaotic lifestyles with ongoing family and living circumstances issues with which they wanted to focus on rather than exploring the past with EMDR. <b>Cautious Optimism:</b> it was felt that EMDR could be useful, but only in the right client at the right time. Client experience and treatment acceptability are crucial factors to select an appropriate treatment. <b>Participant and Researcher Feedback:</b> All patients chose to revert to their normal way of therapy and not pursue EMDR. Despite over a year of stabilization and preparation phases in two patients, they were not able to progress through EMDR to complete the therapy. Therapists suggested that EMDR may be more suitable with clients who have more limited verbal capacities due to consistent feedback from participants about the lack of discussion during the process Difficulties in eye tracking were experienced in two participants resulting in conversion to other forms of bilateral stimulation. Views of therapists and patients undergoing treatment were thought rarely to be sought in research. <b>Sub Groups Outcomes:</b> Not reported	<b>Limitations:</b> <ul style="list-style-type: none"><li>Only one client-psychologist pair undertook desensitizations and reprocessing of past traumatic experiences, meaning views on the experience of EMDR are not representative</li><li>Small sample size meaning views on EMDR may not be generalizable.</li><li>Simplified emotional distress ratings were individual to each patient and not well documented reinforcing the need for standardized protocol validated in individuals with ID</li><li>Specific level of verbal capability not reported</li><li>Lack of information on comorbidities, medications, autism/neurodevelopmental diagnoses and level of verbal communication complicates the ability to generalize generated themes to wider ID population</li><li>Unclear who PTSD and ID diagnoses made by and what assessment tools were used</li><li>Inexperienced therapists with lack of confidence delivering the therapy may have provided EMDR incorrectly, which could have hindered the progress of the participant</li><li>Inclusion of participants with varying severities of ID confounds the opinions on acceptability of EMDR, as more severely impaired participants may report more difficulty tolerating the therapy</li></ul>	<b>GRADE Score 4</b> <ul style="list-style-type: none"><li>Scale to determine severity of PTSD symptoms and whether this reaches the PCL-5/ICD cut off was not used</li><li>Useful to know some of the opinions of patients and therapists, however study design is intrinsically flawed, and conclusions drawn from this are potentially quite misleading</li><li>Future research must work to create standardized protocol and adaptations validated for use in ID</li><li>Participant C02 who tolerated the therapy the best by being the only participant to reach the desensitization stage, also had the lowest ID severity with a borderline-mild diagnosis</li><li>Use of EMDR children's protocol may have yielded better results from participants</li><li>Future studies must homogenize participants to improve generalizability</li></ul>

(Continued)

Table 2. (Continued).

Paper details		Findings	Bias and limitations	GRADE score and comments
<b>Title:</b> Eye Movement desensitization and reprocessing therapy for posttraumatic stress disorder in a child and an adolescent with mild to borderline intellectual disability: A multiple baseline across subjects study		<b>Improvement measures:</b> <b>Primary Outcome</b> = Change in total number of PTSD symptoms. Symptom number gathered from symptom part of the Adapted ADIS-C PTSD questionnaire. Number of symptoms assessed at baseline, prior to treatment, during treatment, after treatment and at 6 weeks follow up. Assessment of whether patients reached PTSD diagnostic criteria was done before and after treatment. <b>Outcome:</b> Both participants reduced their number of symptoms to below the diagnostic cut off for PTSD. This remained the case at 6 weeks follow up. <b>William</b> Baseline = 15.5 symptoms During treatment = 3 symptoms Post treatment and follow up = 2 symptoms <b>Rose</b> Baseline = 14.7 symptoms During treatment = 14.5 symptoms Post treatment and follow up = 4.8 symptoms <b>Participant and Researcher Feedback:</b> Rose experienced new trauma during the baseline PTSD symptoms collection stage complicating the analysis. William had a descending baseline trend but applying Lane and Gast guidelines this is acceptable due to rules of within-condition stability of data. EMDR especially useful in ID because detailed description of events, direct challenging of beliefs, prolonged exposure and daily homework is not required. Anecdotal information was given by carers of both children who reported better mood, improved ability to discuss feelings and enthusiasm to undertake new activities. The parents no longer felt as heavy a burden. Avoidance behaviors were not exhibited by the participants in this study, but the author reports this is common during EMDR therapy due to the preference to avoid traumatic memories. <b>Sub-Groups outcomes:</b> Not reported	<b>Reporting Bias Control:</b> <ul style="list-style-type: none"><li>Independent scoring by second observer on question by question basis</li><li>Bias reduced using inter-rater reliability which showed 95.3% mean agreement (SD = 21.2%) using randomly chosen PTSD symptom interviews</li></ul> <b>Limitations:</b> <ul style="list-style-type: none"><li>Small sample size, as is common with case series, limits the generalizability of results</li><li>Number of PTSD symptoms a crude measure of transformative change and is not a validated way of assessing participants for PTSD diagnosis regardless of the ADIS-C-PTSD being validated for use in ID</li><li>Follow up at 6 weeks may be regarded as a relatively short time before reassessing PTSD diagnosis, conclusions over longer lasting therapeutic effects are limited</li><li>Total number of PTSD symptoms plotted on graphical display and interpreted by visual inspection following guidelines rather than using an analysis of significance</li><li>Details of comorbidities and psychotropic drugs were not provided which could have confounded the results</li></ul>	<b>GRADE score 4</b> <ul style="list-style-type: none"><li>Use of valid and reliable ADIS-C-PTSD assessment for PTSD is novel in this field</li><li>Objective measurements used to allow quantitative analysis of improvement</li><li>Participants with a similar level of ID and who were non-autistic were included in this study helping to create a homogenous population</li><li>Participants assessed for new trauma throughout the process helping to reduce confounding effects of newly developed trauma</li></ul>
<b>Year:</b> 2017				
<b>Country:</b> Netherlands				
<b>Type:</b> Multiple Baseline Across Subjects Study				
<b>Authors:</b> (Meivissen et al., 2017)				

(Continued)

Table 2. (Continued).

Paper details	Findings	Bias and limitations	GRADE score and comments
<p><b>Title:</b> Eye Movement Desensitization and Reprocessing with Adults with Intellectual Disability</p> <p><b>Year:</b> 2014</p> <p><b>Country:</b> USA (Florida)</p> <p><b>Type:</b> PhD Dissertation (Multiple Baseline Across Participants with A-B-A Follow up Design)</p> <p><b>Citation:</b> (Buhler, 2014)</p>	<p><b>Improvement measure:</b>  <b>Primary Outcome Measures:</b> Change in C-PTSD-I and IES-R scores at baseline before therapy, post therapy and at 12 weeks follow up.  C-PTSD-I is a structure interview assessment tool to diagnose different types of PTSD in children and adolescents. The change in number of symptoms in 5 domains was used as to monitor change in C-PTSD-I score. IES-R is a frequently used self-report measure comprised of 15 questions assessing the impact of trauma in 3 domains using a 5 point Likert scale. Change in score across the 3 domains was used to assess outcomes.  <b>Secondary Outcome Measure:</b> PAA-A measured but not discussed here as this does not directly measure PTSD symptoms but rather presence of traits of multiple psychiatric conditions.</p> <p><b>Outcome:</b>  <b>Q50:</b>  <b>C-PTSD-I</b> – Despite experiencing symptoms in every category of the test, the fact that she did not experience significant distress in any area of her life other than frequent avoidance meant she was below the diagnostic cut off pre therapy.</p> <p><b>IES-R -</b>  Baseline: Intrusion (1.0) Avoidance (3.5) Hyperarousal (1.7)  Post Therapy: Intrusion (0.3) Avoidance (2.3) Hyperarousal (1.0)  Follow up: Intrusion (0.6) Avoidance (1.1) Hyperarousal (1.3)</p> <p><b>Q51:</b>  <b>C-PTSD-I</b> – Met criteria pre therapy for PTSD. Trauma exposure (3/4), Reexperiencing (5/11), Avoidance and numbing (5/16), Increased arousal (2/7), Significant distress (1/5); no longer qualified for PTSD diagnosis therapy and follow up.</p> <p><b>IES-R -</b>  Baseline: Intrusion (1.4) Avoidance (0.9) Hyperarousal (0)  Post Therapy: Intrusion (0.6) Avoidance (0.4) Hyperarousal (0)  Follow up: Intrusion (0.1) Avoidance (0.3) Hyperarousal (0)</p> <p><b>Q52:</b>  <b>C-PTSD-I</b> – Met criteria pre therapy, trauma exposure (4/4), Reexperiencing (8/11), Avoidance and numbing (13/16), increased arousal (6/7), Significant distress (3/5); no longer qualified for PTSD diagnosis post therapy and at follow up.</p> <p><b>IES-R -</b></p>	<p><b>Limitations:</b></p> <ul style="list-style-type: none"> <li>It is possible that participants falsely reported improvement for the purposes of wanting to contribute to significant research findings due to demand bias inherent in psychotherapeutic research</li> <li>Two participants completed maintenance and follow up data whilst still in therapy, therefore were not truly followed up</li> <li>Participant Q50 was included in the study but pre therapy fell below the diagnostic cut off for PTSD according to CPTSD</li> <li>Unknowns in population characteristics and classification, Lack of validated PTSD assessment tools used that were validated for use in ID</li> <li>Susceptibility of observer rating scales to inter-rater variability</li> <li>Bias in case analysis interpretation</li> </ul>	<p><b>GRADE score 4</b></p> <ul style="list-style-type: none"> <li>Good attempt made to achieve homogeneity of participants by using highly specific inclusion criteria</li> <li>Very detailed EMDR protocol used that is replicable</li> <li>Detailed PTSD and ID assessments performed</li> <li>All participants received IQ testing before treatment and at follow up to ensure reliability of FSQ result</li> </ul> <p>This was the only study to gather information on verbal IQ to determine severity of verbal deficits</p>

(Continued)

Table 2. (Continued).

Paper details	Findings	Bias and limitations	GRADE score and comments
	Baseline: Intrusion (1.9) Avoidance (2.3) Hyperarousal (1.5) Post Therapy: Intrusion (1.0) Avoidance (1.9) Hyperarousal (0.5) Follow up: Intrusion (1.3) Avoidance (1.1) Hyperarousal (1.2) <b>053:</b> <b>C-PTSD-1</b> – Met criteria pre therapy, trauma exposure (4/4), Reexperiencing (7/11), Avoidance and numbing (9/16), Increased arousal (5/7), Significant distress (5/5); no longer qualified for PTSD diagnosis post therapy and at follow up. <b>IES-R –</b> Baseline: Intrusion (1.1) Avoidance (1.1) Hyperarousal (1.8) Post Therapy: Intrusion (0.6) Avoidance (0.9) Hyperarousal (1.3) Follow up: Intrusion (0.4) Avoidance (0.6) Hyperarousal (0.5) <b>066:</b> <b>C-PTSD-1</b> – Met criteria pre therapy, trauma exposure (3/4), Reexperiencing (3/11), Avoidance and numbing (5/16), Increased arousal (2/7), Significant distress (3/5); no longer qualified for PTSD diagnosis post therapy and at follow up. <b>IES-R –</b> Baseline: Intrusion (2.0) Avoidance (1.5) Hyperarousal (0.8) Post Therapy: Intrusion (1.0) Avoidance (1.0) Hyperarousal (1.0) Follow up: Intrusion (0.6) Avoidance (0.5) Hyperarousal (0.3) <b>068:</b> <b>C-PTSD-1</b> – Met criteria pre therapy, trauma exposure (4/4), Reexperiencing (8/11), Avoidance and numbing (9/16), Increased arousal (7/7), Significant distress (1/5); no longer qualified for PTSD diagnosis post therapy and at follow up. <b>IES-R:</b> Baseline: Intrusion (3.3) Avoidance (3.4) Hyperarousal (3.0) Post Therapy: Intrusion (1.8) Avoidance (1.0) Hyperarousal (0.7) Follow up: Intrusion (0.5) Avoidance (2.2) Hyperarousal (1.4) <b>Participant and Researcher Feedback:</b> All 6 cases showed improvement. No cases had a PTSD diagnosis after treatment, and all improved in a number of dimensions of psychopathology according to the secondary outcome measure on the PAI-A. Each had different overall trajectory and different pattern of relative improvements in the measured dimension. <b>Sub-Groups outcomes:</b> Not reported		

(Continued)



Table 2. (Continued).

Paper details	Findings	Bias and limitations	GRADE score and comments
<p><b>Title:</b> Stepping Stones: EMDR Treatment of Individuals With Intellectual and Developmental Disabilities and Challenging Behavior</p> <p><b>Year:</b> 2010</p> <p><b>Country:</b> USA</p> <p><b>Type:</b> Case Series</p> <p><b>Citation:</b> (Barol &amp; Seubert, 2010)</p>	<p><b>Improvement measures:</b></p> <p><b>Primary Outcome:</b> Biographical timeline created for each patient to identify areas to target in EMDR therapy. Improvement in PTSD symptoms due to these targets measured using client self-reporting, caregiver observations, pre and post therapy evaluations using bespoke PTSD assessment tool and on-going in session response scaling.</p> <p><b>Outcome:</b></p> <p><b>Teresa:</b></p> <p><b>Symptoms and Trauma</b> – Not reported</p> <p><b>Pre therapy</b> – Inappropriate reaction to criticism and unable to remember feelings of self-worth.</p> <p><b>Post therapy</b> – Last processed event SUD remained at absolute zero at last session. Desensitized several traumatic memories. Teresa felt more able to remember feelings of self-worth</p> <p><b>Follow up at 3 and 6 months</b> – Not reported</p> <p><b>James:</b></p> <p><b>Symptoms and Trauma</b> – flashbacks, nightmares, anger outbursts, avoidant behavior, frequent startle response, sexual obsession and self-hitting</p> <p><b>Pretherapy -</b></p> <p>14/19 on PTSD Checklist;</p> <p>30/59 on Psychiatric Questionnaire;</p> <p>8/32 on Behavioral Symptoms Cross Reference list</p> <p><b>Posttherapy –</b></p> <p>2/19 on PTSD Checklist;</p> <p>9/59 on Psychiatric Questionnaire;</p> <p>0/32 on Behavioral Symptoms Cross Reference list</p> <p>The authors report that James no longer qualified for PTSD diagnosis. James reported absence of pre-treatment sexual abuse-related trauma symptoms from parents and client.</p> <p><b>Follow up at 3 and 6 months</b> – No disturbance regarding abuse itself at both reviews and maintenance of symptom disappearance.</p> <p><b>Tom:</b></p> <p><b>Symptoms and Trauma:</b> Experienced death of mother at age 12 and remarriage of father twice, the first of which led to divorce. Became very attached to father's 3rd wife.</p> <p><b>Pretherapy</b> – Limited interpersonal exchange and anger outbursts</p> <p><b>Posttherapy</b> – BLS during sessions successfully calmed patient down during anger outburst. One anger outburst successfully managed within 30 minutes, usually outbursts last hours/days.</p> <p><b>Follow up at 3 and 6 months</b> – Not reported</p> <p><b>Kate:</b></p> <p><b>Symptoms and Trauma:</b> Three eye operations and multiple ear operations during the first two years of her life which she found traumatic. Experienced violence from a peer at school who triggered a code red alarm resulting in a fear of going to school. Hypervigilance resulted from this experience.</p> <p><b>Pretherapy</b> – Severe perseverative self-talk and violent kicking episodes toward others.</p>	<p><b>Limitations:</b></p> <ul style="list-style-type: none"> <li>● Poor outcome descriptions for most participants</li> <li>● Unclear in Teresa what traumatic experiences she has had; her PTSD symptoms were not clearly stated, and she had neither follow up nor evidence of formal evaluation of PTSD symptoms</li> <li>● Diagnostic threshold scores for PTSD not discussed in this paper</li> <li>● Limited by case series design with confounding variables: not controlled</li> <li>● EMDR administered alongside existing care package making it difficult to know if positive effects were due to EMDR alone</li> <li>● Only psychiatric comorbidity details given but physical comorbidity can also impact on efficacy of EMDR</li> <li>● Mixed and inconsistent reporting of outcomes and PTSD assessment; this study does not present quantitative analysis from bespoke tool for all patients except for James</li> <li>● Mentions use of a 59 item psychiatric questionnaire and list of generic symptoms of PTSD in ID, but does not give references of where to find information on this assessment tool</li> <li>● Bespoke tool not replicable in other studies as not well enough described</li> <li>● Authors mention use of SUD and VOC scores to monitor improvement, however this is not useful in aiding PTSD diagnosis as these scales relate only to the EMDR process</li> <li>● Heterogeneity of participants high with a mixture of autism diagnoses, level of verbal communication and comorbidity which could confound the efficacy of EMDR</li> </ul>	<p><b>GRADE score = 4</b></p> <ul style="list-style-type: none"> <li>● This paper is the first to state the IQ scores and limitations in global functioning are not representative of the psychosocial and overall intellectual capacities of a person</li> <li>● Rhythmic stimulus of BLS was reported as cathartic in Tom and Kate, the action of BLS was able to reduce the distress of Tom rather than the therapy itself</li> <li>● Due to Tom and Kate's limited verbal capabilities, therapists focussed on present issues as they were not able to focus the participants on making connections to past trauma</li> <li>● Mark required the development of rapport through several sessions before EMDR treatment to make him amenable to treatment,</li> <li>● Mark used Harry Potter imagery of mind control to make understand the importance of doing EMDR, a unique method of helping the patient to understand the process</li> <li>● This research focuses mainly on the use of EMDR in challenging behavior rather than in PTSD</li> </ul>

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Table 2. (Continued).

Paper details	Findings	Bias and limitations	GRADE score and comments
	<p><b>Posttherapy</b> – No clear improvement apart from positive calming reaction during therapy when BLS was administered</p> <p><b>Follow up at 3 and 6 months</b> – Not reported</p> <p><b>Mark:</b></p> <p><b>Symptoms and Trauma</b>- Recurrent hospitalizations for depression each year occurring around time of birthday. Birthday associated with tragic suicide of brother and father. Lack of eye contact, anxiety, irritability, thought perseveration and rageful outbursts.</p> <p><b>Pretherapy</b> – Screaming at peers triggered by social situations and unable to build romantic relationships</p> <p><b>Posttherapy</b> – Maintaining a relationship and two part time jobs. Higher level of functioning reported in general. Screaming outbursts greatly reduced with staff confirming these changes. Improved eye contact by the end of therapy.</p> <p><b>Follow up at 3 and 6 months</b> – Hospitalization-free for 5 years after</p> <p><b>Antony:</b></p> <p><b>Symptoms and Trauma</b>- Death of mother who Antony found under a bridge. Spent many years in foster care. He felt that he could have helped his mother if he knew earlier and held a negative belief that he was a bad son for this reason. Abusive and unfair treatment from staff in foster care.</p> <p><b>Pretherapy</b> – Yelling, property destruction, crying, depressed periods and fear of institutionalization</p> <p><b>Posttherapy</b> – Fear of institutionalization disappeared, replaced belief that he was a bad son with good son and done his best. Negative disturbance around experience with mother was removed. Cried as model employee by employer and job coach.</p> <p><b>Follow up at 3 and 6 months</b> – Symptom relief maintained over next 5 years.</p> <p><b>Participant and Researcher Feedback:</b></p> <p>For Teresa, SUD scores between the end of one session and the start of the next increased, implying that memories became more disturbing at the start of the next session despite the reprocessing that previously occurred. This is highly unusual in EMDR. The client may have wanted to please the therapist by reporting better distress scores at the end of the session than were truly felt. Could also be due to the difficulty that IDD have in generalizing learning and sustaining new learning when faced with life triggers and challenges.</p> <p>Greater intellectual disability with increasing severity of coexisting diagnosis seemed to mean less generalization of positive cognitions formed in EMDR sessions to the rest of life.</p> <p>Significant calming reported when BLS applied during heightened irritability or arousal in sessions.</p> <p>Greater disability was felt to manifest in a more compromised attention span</p> <p><b>Sub-Groups outcomes:</b></p> <p>Two autistic patients were not able to focus on or make connections to past events</p>		

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Table 2. (Continued).

Paper details		Findings	Bias and limitations	GRADE score and comments
Title:		Improvement measure:	Limitations:	GRADE score = 4
<b>EMDR Treatment in People with Mild ID and PTSD: 4 Cases</b>		<b>Primary Outcome:</b> Subjective feedback from pre and posttherapy assessments, and review to see change in symptoms as reported by carers and patients. Review of whether patient met criteria for PTSD after treatment. Follow up at varying lengths of time was done to assess for improvement maintenance.	Doesn't quantify which aspects of PTSD symptoms were reduced	
<b>Year:</b> 2011			Subjective reporting of symptom progression means change in PTSD symptom severity is not quantifiable, and therefore comment on efficacy cannot be made	
<b>Country:</b> Netherlands		<b>Outcome:</b> All four clients after treatment did not reach diagnostic criteria to diagnose PTSD according to DSM-IV-TR and DM-ID.	Varying levels of assessment at follow up means inconsistent reporting of outcomes	
<b>Type:</b> Case Series			PTSD diagnosis seems apparent	
<b>Citation:</b> (Meuwissen et al., 2011a)		<b>John:</b> Symptoms and Trauma – Severe scooter accident, end of relationship to which he responded by hitting his partner, low mood, accused of and psychologically treated for sexual abuse, divorce of parents)	Heterogeneity of populations means participants can't be compared to each other reliably	
		<b>Pretherapy</b> – Frightened when confronted with accident-related stimuli, anniversary effect, easily upset, intestinal somatic symptoms, slow pace, avoidance of activities, inability to accept criticism	Only psychiatric comorbidity mentioned, but physical can also impact on EMDR efficacy	
		<b>Posttherapy</b> – Able to think about traumatic memories without getting upset	Author reports all mild ID participants but scale definitions report variation from borderline to moderate	
		<b>Follow up at 4 months</b> – Disappearance of avoidance behavior, taking up more activities, decreased anger outbursts, physical complaints decreased	Communication was tailored to the individual meaning non-standardized protocol was used for EMDR	
		<b>Follow up at 32 months</b> – Results maintained and client had built a stable relationship	Slightly differing levels of ID in this cohort means different baseline levels of cognitive and communication abilities, therefore efficacy of EMDR is confounded	
		<b>Mitchell:</b> Symptoms and Trauma – Witnessed car fire, throwing objects when hearing voices; threatened by an abusive man where police did not respond, witnessing domestic violence, parents divorced, outplacements	Different method of assessing IQ given to Mary who was not given a score for the total IQ component of the WISC-R and only a verbal IQ score	
		<b>Pretherapy</b> – Fears, obsessive compulsive behavior, hears voices, reality and fantasy difficult to distinguish, avoids sleeping at parental home, visiting parental home accompanied with outbursts of aggression		
		<b>Posttherapy</b> – Able to visit parental home without problems, more relaxed, obsessive and compulsive behaviors decreased		
		<b>6 weeks</b> – Results maintained and able to sleep at parental home without problems		

(Continued)

Table 2. (Continued).

Paper details	Findings	Bias and limitations	GRADE score and comments
	<p><b>Follow up at 3 months</b> – Results maintained, behavioral problems disappeared completely, medication phased out</p> <p><b>Follow up at 18 weeks</b> – Results maintained</p> <p><b>Mary:</b></p> <p><b>Symptoms and Trauma:</b> Childhood troubles at school, repeated witnessing of domestic violence, witnessed father's death, divorced twice, experienced death of mother, emergency hospital admission, various surgeries</p> <p><b>Pretherapy</b> – Panic attacks often followed by hospitalization, physical complaints when distressed, easily upset, persistent anger, nightmares, obsessive thoughts, hearing voices, avoiding places</p> <p><b>Posttherapy</b> – Panic attacks disappeared, sleep problems disappeared, mentally relaxed, initiating activities, social relationships improving, keeping calm when physical complaints and medical treatments, disturbing thoughts disappeared</p> <p><b>Follow up at 6 and 13 months:</b> Results maintained</p> <p><b>Eve:</b></p> <p><b>Symptoms and Trauma:</b> Death of two close family members, three suicide attempts of father's best friend, serious illness of school friend</p> <p><b>Pretherapy</b> – Fears, compulsive behavior, outbursts of anger, frequent mood change, disturbing thoughts about illness/knives/death</p> <p><b>Posttherapy</b> – Disturbing thoughts disappeared</p> <p><b>Follow up at 7 weeks</b> – results maintained and more often cheerful and significant decrease of anger outbursts, more relaxed</p> <p><b>Follow up at 3 months</b> – Results maintained</p> <p><b>Participant and Researcher Feedback</b></p> <p>PTSD symptoms present for 3–17 years and dissipated after 2–13 EMDR sessions across all participants.</p> <p>Findings need to be considered in light of difficulty of diagnosing PTSD in ID individuals. Inability for client to convey PTSD criterion A2 symptoms in DSM-IV-TR seems to be an overwhelming problem in this field. In particular clients with autism who express feelings in an atypical way. Only Mitchell and Mary were able to self-report feelings of horror, helping to diagnose criteria A2. There exists difficulty in interpreting the severity of distress of PTSD symptoms in ID.</p> <p>Posttherapy, all caregivers reported positive changes in terms of improving independence, taking up activities and learning new skills, except for Eve.</p> <p><b>Sub-Groups outcomes:</b></p> <p>Mitchell and Eve were previously misdiagnosed as MCDD, attributing psychotic episodes to MCDD. However, retrospectively symptoms are now attributed to PTSD.</p> <p>In John and Mary, decrease in physical complaints and increase in social/adaptive skills facility. Depressive symptoms in Mary and Eve decreased.</p>		

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Table 2. (Continued).

Paper details	Findings	Bias and limitations	GRADE score and comments
<p><b>Title:</b> Do persons with intellectual disability and limited verbal capacities respond to trauma treatment?</p> <p><b>Year:</b> 2011</p> <p><b>Country:</b> Netherlands</p> <p><b>Type:</b> Case Series</p> <p><b>Citation:</b> (Meuwissen et al., 2011b)</p>	<p><b>Improvement measure:</b>  <b>Primary Outcome:</b> Subjective reporting of symptoms from caregivers and interpretation by clinical psychologist.</p> <p><b>Outcome:</b>  <b>Maria:</b>  <b>Symptoms and Trauma</b> – Sexual abuse by 2 perpetrators, outplacement in crisis unit due to inability for parents to cope, parents divorced  <b>Pretherapy</b> – Restless, overly possessive of mother, sleeping issues, aggressive outbursts, tearful, bad personal hygiene, obsessive behavior;  <b>Posttherapy:</b> No longer restless, obsessive behavior disappeared, sleeping pattern normalized, positive mood returned, aggression disappeared, personal hygiene normalized; <b>Follow up at 4 months</b> – Results maintained  <b>Follow up at 32 months</b> – Results maintained with increased self-sufficiency</p> <p><b>Simon:</b>  <b>Symptoms and Trauma:</b> Death of mother 10 months prior, death of father in adolescence of heart attack, courtship broken up forced by others, new trauma arose after 4<sup>th</sup> EMDR session where Simon became lost for 2 days on a trip abroad and was found in police station  <b>Pretherapy</b> – Aggressive outbursts with knives since death of mother, shaking, complaining, possessive of caregivers and girlfriend, excessive eating  <b>Posttherapy</b> – Self-sufficiency increased, able to talk about mother appropriately, more relaxed, excessive rage disappeared, asked for assistance when in trouble, able to talk about thoughts and feelings.  <b>Follow up at 10 months</b> – Results maintained</p> <p><b>Participant and Researcher Feedback:</b>  SUD level in both clients brought back to 0. The need for further exploration of EMDR applicability in severe ID was acknowledged. Concern for safety of clients undergoing treatment due to creation of emotionally charged situations is debunked by this study. None of the clients exhibited maladaptive responses to EMDR. Authors hint at the need for completion of multiple baselines study with development of valid and reliable instruments for assessment of PTSD in people with ID and use of experienced EMDR specialists. The authors suggest that the more limited a person's verbal capability, the more difficult assessment will be.</p> <p><b>Sub-Groups Outcomes:</b>  Not Reported</p>	<p><b>Limitations:</b></p> <ul style="list-style-type: none"> <li>● Subjective reporting of symptoms as assessed by person administering and overseeing EMDR</li> <li>● No objective scales used to assess outcomes.</li> <li>● Same practitioner administered and dealt with both cases in this report which could have introduced bias</li> <li>● Due to limited verbal capacity of participants and cognitive disability, complaint-related changes had to be reported by caregiver at beginning of each session to track progress, which may confound the true opinions of participants</li> <li>● Different measures used to assess ID in both patients</li> <li>● Level of limitation of verbal capacities not quantified</li> <li>● Citations giving sources of ID scales used not given</li> <li>● Not reported whether Maria had a diagnosis of Autism, only stated that she had symptoms</li> <li>● Details of physical comorbidities not given</li> <li>● Medication details for Simon not given</li> <li>● Communication tailored to each participant leading to non-standardized protocol</li> </ul>	<p><b>GRADE score = 4</b></p> <ul style="list-style-type: none"> <li>● Simon was able to resolve initial complaints after 4 sessions, with new trauma occurring during sessions requiring only one extra session of EMDR to resolve</li> </ul>

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Table 2. (Continued).

Paper details		Findings	Bias and limitations	GRADE score and comments
<b>Title:</b> Treatment of PTSD in people with severe intellectual disabilities: A case series				
<b>Year:</b> 2012				
<b>Country:</b> Netherlands				
<b>Type:</b> Case Series				
<b>Citation:</b> (Meuwissen et al., 2012)				
<b>Improvement measure:</b> <b>Primary Outcome:</b> Symptom changes in participants were taken as a history over the course of therapy, at the end of therapy and at follow up to determine effectiveness of EMDR. <b>Outcome:</b> <b>Jane (underwent two rounds of therapy labeled pre/posttherapy 1 and pre/posttherapy 2):</b> <b>Symptoms and Trauma</b> – Traumatic experience involving Jane's head stuck in the metal bars of her bed requiring removal by fire brigade <b>Pretherapy 1</b> – Midnight screaming episodes, sleeping problems, physical complaints, adaptive skills decline, muscle tightness <b>Posttherapy 1</b> – Screaming episodes stopped completely, Sleep issues resolved, Physical pain decreased, pain medication discontinued, muscles more relaxed, enjoyed a more frequent cheerful mood. Persistent episode of sadness each week persisted <b>Follow up at 7 months</b> – Improvements maintained with persistence of weekly sadness episodes <b>Pretherapy 2</b> – Referred for treatment again 7 months later due to episodes of tearfulness that were inconsolable and not being able to stop talking about mother <b>Posttherapy 2</b> – Weekly episodes of sadness improved as well as tearfulness after 3 EMDR sessions. <b>Follow up at 6 weeks</b> – Results remained at this mark with positive effects remaining in terms of sleep disturbance. Effects from first round of therapy 15.5 months after being referred for first time maintained. <b>Melissa:</b> <b>Symptoms and Trauma</b> – Life threatening hospitalization episodes <b>Pretherapy</b> – Panic attacks, anxiety, poor concentration, volatile, easily upset, physically tense, cried 'no doctor' every time she left home to get in the car <b>Posttherapy</b> –			<b>Limitations:</b> <ul style="list-style-type: none"><li>● Participants unable to self-report feelings in the face of traumatic events so application of PTSD criterion A2 was not given as first-hand experience for the participants</li><li>● For two clients, the caregivers were present and reported how they appeared to feel at the time of trauma, meaning an inaccurate account of symptoms may have been given</li><li>● Severity of ID may have complicated PTSD assessment as PTSD symptoms seem to vary with degree of ID</li><li>● Degree of maintenance of positive effects of EMDR not measured objectively at follow up</li><li>● Quantitative assessment tools not used meaning bias may have been introduced from subjective feedback given from verbal interviews used</li><li>● Quantitative measure of ID severity not given</li><li>● Jane was on pain medication which suggests she might suffer from chronic pain, a comorbidity which might have affected how successful EMDR was for her; she was also the only participant to have two rounds of EMDR therapy</li><li>● Same person performed EMDR therapy and assessed therapeutic process, meaning bias may have been introduced</li><li>● Protocol for EMDR and assessment not standardized for each patient which may have confounded the results</li></ul>	<b>GRADE score = 4</b> <ul style="list-style-type: none"><li>● Quantitative analysis not performed to compare cases</li><li>● Pain medication in Jane was discontinued after EMDR therapy</li><li>● Joany during therapy displayed a maladaptive response involving barricading herself in her room at night appearing to shout at the perpetrator of her abuse</li></ul>

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Table 2. (Continued).

Paper details	Findings	Bias and limitations	GRADE score and comments
	<p>Stopped crying 'no doctor', panic decreased, tolerated checkups and treatment, improved concentration, enjoyed positive mood states more easily, learnt new skills</p> <p><b>Follow up at 2.5 years</b> – Results maintained</p> <p><b>Peter.</b></p> <p><b>Symptoms and Trauma</b> – Eating problems coinciding with development of severe heart problems and traumatic hospitalization</p> <p><b>Pretherapy</b> – Eating problems, aggressive outbursts, refusal to eat solid food independently, requires someone else to feed, eats only when combined with another activity</p> <p><b>Posttherapy</b> – During last session was able to tolerate listening to the story of his hospitalization without distress</p> <p><b>Follow up at 3 months</b> – Aggressive outbursts faded, displayed greater ability to eat independently, learnt new skills, more self sufficient</p> <p><b>Follow up at 2 years</b> – Eating solid food independently</p> <p><b>Joany.</b></p> <p><b>Symptoms and Trauma</b> – Sexual and physical abuse by group member in group home</p> <p><b>Pretherapy</b> – Severe behavioral problems, general anxiety, exaggerated startle response, panic attack when hearing sneezes or coughs, restless, bad mood usually, tired and passive, unpredictable aggressive outbursts, afraid of dark, physical attacking other people, nightmares, intolerance to being touched</p> <p><b>Posttherapy</b> – More cheerful, energy increased, tolerated crowded environments, tolerated touch, able to look at photos of perpetrator and group home where incidents happened without distress</p> <p><b>Follow up at 3 months</b> – Aggressive outbursts reappeared with maintenance of other posttherapy improvements</p> <p><b>Participant and Researcher Feedback</b></p> <p>ID complicates the assessment of PTSD. Criteria A2 symptoms on the DMS-IV-TR are difficult to report as participants in this study are less able to self-report their feelings. Criteria B symptoms on the DSM-IV-TR are difficult to assess as symptoms which may appear intrusive as a result of PTSD may be purely the result of ID. However, two clients experienced easily recognizable intrusive symptoms of reexperiencing. Criterion C symptoms on DSM-IV-TR are difficult to assess due to limited verbal capacity of clients.</p> <p><b>Sub-Groups Outcomes:</b></p> <p>Not reported</p>		

(Continued)

Table 2. (Continued).

Paper details		Findings	Bias and limitations	GRADE score and comments
<b>Title:</b> Eye movement desensitization and reprocessing in an adolescent with epilepsy and mild intellectual disability <b>Year:</b> 2009 <b>Country:</b> Netherlands <b>Type:</b> Case Report <b>Citation:</b> (Rodenburg et al., 2009)		<b>Improvement measure:</b> <b>Primary Outcome:</b> Dutch IES score used to monitor change in PTSD symptoms. Trauma symptoms assessed 1 week before start of EMDR and 2 weeks after end of EMDR. Reliable change index (RCI) used to assess if change in score over time was significant. <b>Outcome:</b> <b>Tom:</b> <b>Symptoms and Trauma</b> – Severe physical abuse throughout childhood manifesting in flashbacks and sleep disturbance. Tom experienced sleeping difficulty, frequent nightmares, flashbacks and suicidal ideation. <b>IES Pretherapy</b> = 52 <b>IES Posttherapy</b> = 18 <b>RCI</b> = 3.88 <b>P-value</b> = 0.0001 Tom no longer qualified for PTSD diagnosis posttherapy as his score was below the threshold of 26. RCI was above the critical value of 1.96, indicating a significant reduction in PTSD symptoms. <b>Participant and Researcher Feedback</b> Purpose of the EMDR was to work on the most traumatic memory and move onto others. After 5 sessions Tom felt it was not necessary as other traumatic memories had decreased. <b>Sub-Groups outcomes:</b> Not reported	<b>Limitations:</b> <ul style="list-style-type: none"><li>● Follow up measurements not conducted, therefore effects of EMDR over time remain unclear.</li><li>● Tom held core values of strength and being unbeatable, which may have overestimated the true reduction in IES in this patient</li><li>● EMDR administered alongside existing care package making it difficult to know if positive effects were due to EMDR alone</li><li>● Case report design of study limits the generalizability of results</li><li>● IES scale used not tested for use in ID</li></ul>	<b>GRADE score = 4</b> EMDR initiated as a result of PTSD diagnosed during an inpatient admission

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Table 2. (Continued).

Paper details		Findings	Bias and limitations	GRADE score and comments
<b>Title:</b> Eye movement Desensitization and Reprocessing in the treatment of trauma with mild intellectual disability: a case study <b>Year:</b> 2014 <b>Country:</b> UK <b>Type:</b> Case Report <b>Citation:</b> (Dilly, 2014)		<b>Improvement measure:</b> <b>Primary Outcome:</b> Change in PDS scores measured before treatment, immediately after treatment and at 1 and 6 months follow up. <b>Outcome:</b> <b>Simon:</b> <b>Symptoms and Trauma</b> – Significant history of chaotic and dysfunctional family upbringing. Placed in care as teenager. Physical and sexual childhood abuse. Abuse over long time period by number of people. Trauma due to an event involving fire which brought him close to death. This EMDR set focussed on the trauma relating to his experience with fire. <b>PDS Pretherapy</b> = 16/17 symptoms and 45/50 severity <b>PDS Posttherapy</b> = 7/17 symptoms and 9/50 severity <b>PDS at 6 months follow up</b> = 8/17 symptoms and 8/50 severity <b>Participant and Researcher Feedback:</b> Positive qualitative feedback given from Simon showing that EMDR was well tolerated. EMDR helped enable to get things off Simon's mind, and he feels okay talking about what happened with regards to the fire. Can watch TV programmes or news discussing fire without getting upset. He is no longer phased when fire alarms go off. Simon feels safer when locked in room at night. He does not have bad dreams or nightmares about being locked in room and thinking he's going to die. Statistical analysis not appropriate in this case study according to author. Reduction in symptoms in all three core clinical subgroups, reexperiencing, avoidance and arousal, outcomes maintained at 6 months follow up. Reduction in strength rating most prominent in avoidance domain. <b>Sub-Groups Outcomes:</b> Not reported	<b>Limitations:</b> <ul style="list-style-type: none"><li>● PDS designed to estimate impact of a single life event only, but this participant had multiple traumas</li><li>● PDS scores represented graphically but not as raw data. Slightly confusing to determine the Raw PDS scores post treatment</li><li>● It is possible that self reported distress levels were related to additional lifetime trauma experiences and not just the fire which the EMDR focussed on</li><li>● Case report design limits generalizability of results</li><li>● Positive outcomes based only on self reported symptoms and consideration should be given to social desirability effect and propensity to validate outcome of therapy</li><li>● Unclear what the PDS score threshold is for PTSD diagnosis</li><li>● Information on comorbidities and medication not given which may have confounded the results</li><li>● EMDR protocol used in this study is not replicable as limited information is given</li><li>● PDS assessment tool not tested for use in ID</li></ul>	<b>GRADE score = 4</b> <ul style="list-style-type: none"><li>● PDS modified with minor adjustments and simplifications to suit the level of understanding of the participant</li></ul>

(Continued)



Table 2. (Continued).

Paper details		Findings	Bias and limitations	GRADE score and comments
<b>Title:</b> EMDR treatment for PTSD and intellectual disability: a case study <b>Year:</b> 2015 <b>Country:</b> UK <b>Type:</b> Case Report <b>Citation:</b> (Barrowcliff & Evans, 2015)		<b>Improvement measure:</b> <b>Primary Outcome:</b> Change in symptoms on DSM IV TR and clinical interview using CRIES-13 to provide evidence of improvement. <b>Outcome:</b> <b>Symptoms and Trauma</b> – House fire which required her to be carried out of a burning building, and the experience of being taken in an ambulance to hospital after the fire. Hypervigilance, self-harm in the form of hand biting, elevated distress and frequent checking behaviors Intrusion <b>Pretherapy</b> – 5/5 intrusion symptoms, 5/5 avoidance symptoms <b>Posttherapy</b> – 1/5 intrusion symptoms, 0/5 avoidance symptoms <b>Follow up</b> – Not reported Significant improvement in verbal responses on CRIES-13 interview. Return of symptoms back to baseline levels of irritability and concentration, similar to how they were before the traumatic event occurred. Hyper vigilance disappeared and startle response reduced after therapy. Ethel no longer qualified for PTSD diagnosis after intervention. Although Ethel decline follow up, review of broader health files showed no signs of reemergence of trauma symptoms. <b>Participant and Researcher Feedback:</b> High possibility of communication issues, misattributing symptoms and diagnostic overshadowing in a cohort of ID patients. Failure that NICE guidance does not encompass for ID population. <b>Sub-Groups outcomes:</b> Not reported	<b>Limitations:</b> <ul style="list-style-type: none"><li>● PTSD IV TR results not discussed in great depth in the study, doesn't clearly state how she met the criteria for diagnosis</li><li>● Unclear who diagnosed ID and what severity and what scale used</li><li>● Unable to complete VOC and SUD scales due to lack of understanding</li><li>● Unable to use hands spread method to indicate distress and validity</li><li>● Other objective measures were not tolerated</li><li>● Limited communication of whether things were "better or worse" was used providing some insight into improvement which is highly subjective</li><li>● No follow up done to see lasting impacts of EMDR due to Ethel declining</li><li>● Information on medications not given which could have confounded the effects of EMDR</li></ul>	<b>GRADE score = 4</b> <ul style="list-style-type: none"><li>● Very detailed adaptation schedule to normal EMDR documented which can be replicated</li></ul>

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Table 2. (Continued).

Paper details		Findings	Bias and limitations	GRADE score and comments
<b>Title:</b> Left Out and Left Behind: EMDR and the Cultural Construction of Intellectual Disability		<b>Improvement measure:</b> <b>Primary outcome:</b> Subjective feedback from clinical interview <b>Outcome:</b> <b>Mitchell:</b> <b>Symptoms and Trauma</b> – Internalized shame-based stigma resulting from his peers and family members succeeding whilst he lagged behind. Painful rejection experienced when Mitchell's friend went to Disney Land without him. <b>Pretherapy</b> – Best friend went on a trip to Disney land without him leading to feelings of rejection which tapped into his internalization of shame-based stigma leading him to feel inadequate compared to his siblings <b>Posttherapy</b> – Client reported that he felt "really good" and no longer felt feelings of rejection, feelings of love and friendship for Justin overshadowed the feelings of rejection. <b>Follow up</b> – Not reported <b>Jamie:</b> <b>Symptoms and Trauma</b> – Traumatic memory of mother pouring boiling water onto her. <b>Pretherapy</b> – Not reported <b>Posttherapy</b> – Not reported <b>Follow up</b> – Not reported <b>Vanessa:</b> <b>Symptoms and Trauma</b> – Excessive lying and thought to be playing games with those around her in a bid to get attention. Little emotional awareness and tolerance for anxiety and panic. Episodes of crying for help where she threatens self-harm and suicide. Sometimes experiences flashback episodes. Experienced an experience of sexual coercion in high school. <b>Pretherapy</b> – Not reported <b>Posttherapy</b> – Not reported <b>Follow up</b> – Not reported <b>Participant and Researcher Feedback:</b> Jamie experienced a severe adverse reaction to EMDR. After two brief sets of BLS a sudden change in behavior occurred. A change in body language and facial expression from open and smiling to terror, eyes downcast and facial muscles clenched occurred. Jamie fled the treatment room and hurled herself in front of a car. Dissociative identity disorder and ID in the clinical experience of the author are not mutually exclusive, despite low intelligence being thought to determine no possibility of being able to let this occur. Diagnostic overshadowing prevalent in ID populations in terms of dissociative episodes as a result. Research must assess how trauma impacts those with ID, how difficult it is for those with ID to access EMDR therapy and evaluate the effectiveness of adjusted protocols with validation studies to follow. <b>Sub-Groups Outcomes:</b> Not reported	<b>Limitations:</b> <ul style="list-style-type: none"><li>● No objective measure of improvement used</li><li>● Case descriptions incomplete</li><li>● Mitchell's case is the only one with enough evidence provided to gain an idea of whether EMDR was effective</li><li>● Little information given on comorbidities, medication, PTSD/ID diagnostic criteria and individual EMDR protocol</li><li>● Difficult to draw conclusions from this chapter as solid evidence on outcomes has not been reported</li></ul>	<b>GRADE score = 5</b> <ul style="list-style-type: none"><li>● PTSD diagnosis not required for EMDR to be effective in ID hinted in this book chapter</li><li>● Perhaps much lower threshold for what constitutes a traumatic memory in ID, therefore PTSD criteria for this group needs to be rewritten</li><li>● More of a descriptive piece from which a severe reaction to EMDR is described in Jamie, providing evidence that it is not always tolerated</li></ul>
<b>Year:</b> 2017				
<b>Country:</b> USA (NY)				
<b>Type:</b> Book Chapter containing 3 case studies				
<b>Citation:</b> (Yaskin & Seubert, 2017)				

(Continued)

Table 2. (Continued).

Paper details	Findings	Bias and limitations	GRADE score and comments
<b>Title:</b> EMDR with Clients with mental Disability <b>Year:</b> 2005 <b>Country:</b> USA (NY) <b>Type:</b> Book Chapter Using Details of Case Study <b>Citation:</b> (Saubert, 2005)	<b>Improvement measure:</b> <b>Primary Outcome:</b> Subjective feedback and visual observation of change from EMDR practitioner. <b>Outcome:</b> <b>Michael:</b> <b>Symptoms and Trauma</b> – Suspended from school as he threatened to get a gun and shoot people, yell in love with a girl at school (became convinced she was his girlfriend) then became angry and jealous when she was with her current boyfriend, best friend stopped returning his phone calls which was aggravating and hurtful. <b>Pretherapy</b> – Possessed feelings of shame, loss and anxiety. Withdrawal from social situations and acting out emotions of fear and hurt stemming from rejection of girlfriend. Felt frustrated at his hearing impairment. <b>Posttherapy</b> – No disturbance when talking about situation with girlfriend or hearing impairment <b>Follow up at 1 year</b> – Results maintained <b>Carol:</b> <b>Symptoms and Trauma</b> – Death of multiple family members and friends over the preceding year. <b>Pretherapy</b> – Acting out aggressively when asked how she is feeling or whether someone has died. <b>Posttherapy</b> – Better able to manage aggression episodes <b>Follow up at 1 year</b> – Not reported <b>Participant and Researcher Feedback:</b> Thorough interviewing and collateral histories from caregivers and family members with involvement in the whole process. Recognition that smaller trauma not considered as trauma which defines PTSD may still be causing enough symptoms to cause ID individuals PTSD-like symptoms. Compassionate guesswork often required filling in the gaps. Facilitate communication by recognizing verbal, facial, body-centered, movement, posture, art and music languages to help the client convey their thoughts and emotions. Facilitate recognition of emotional states as caregivers often shield the client from their feelings in attempt to protect them. Challenge the client so that they are not emotionally limited and compliant as they tend to be in ID. VOC and SUD often need a great deal of adaptation, using worded and descriptive scales rather than abstract number scales Affect tolerance much lower in ID clients. frequent verbal directions to imagine safe space if things become intolerable. Reduced attention span in ID clients. <b>Sub-Groups outcomes:</b> Not reported	<b>Limitations:</b> <ul style="list-style-type: none"><li>● This book chapter cannot be used to make conclusions about whether EMDR is effective as outcomes were not measured, no improvement measures used, and limited information given on the participants</li><li>● Level of verbal communication not stated</li><li>● Unclear what IQ scale was given to Michael</li><li>● Unclear what PTSD and trauma tools were used for assessment</li></ul>	<b>GRADE score = 5</b> <ul style="list-style-type: none"><li>● Very difficult to use the case study in this chapter to make conclusions as the process is not coherent and not enough detail given</li><li>● This book chapter is better used as a descriptive piece alongside research to aid the process of EMDR</li><li>● Important information given in this book chapter on the necessary adaptations and concepts required to perform EMDR in ID</li></ul>

Table 3. Summary of methods, results, discussion, limitations and conclusions, and the author's general comments for each publication identified of literature review design.

Paper details:				
Title:	Search Sources:	Method:	Results:	Discussion:
Eye Movement Desensitization and Reprocessing (EMDR) for DSM-5 Posttraumatic Stress Disorder (PTSD) in adults with intellectual disabilities: A case study review	Nine databases searched: Cochrane library, Medline, CINAHL, PubMed, Web of Science, Wiley Online Library, PsycINFO, PILOTS, Psychology and Behavioral Science. References of all related articles searched for literature. <b>Date Ranges:</b> Search conducted April-May 2014 with inclusion dates 1987–2014 Search ran in October before submission to check for new papers <b>Terms:</b> 7 PTSD terms 11 ID terms 6 EMDR terms <b>Method of Appraisal:</b> Key questions were posed in the aims and objectives and systematically answered.		<b>Exclusion:</b> 156 citations yielded; 132 excluded as not of case study design; 18 excluded as not from peer reviewed journal, not EMDR therapy or not in English <b>Literature identified:</b> 6 case studies identified after exclusion criteria applied: (Barol & Seubert, 2010; Dilly, 2014; Mevissen et al., 2011a, 2011b, 2012; Rodenburg et al., 2009)	<b>Assessment of trauma in adults with ID:</b> Child Trauma questionnaire and live events checklist are tools used in the case studies reviewed but have limitations when assessing people with ID. Retrospective analysis difficult in ID therefore giving these questionnaires may not yield accurate results. Simplification of language may be necessary of these tests or have caregivers give assessment on behalf. <b>Assessment of PTSD in adults with ID:</b> PTSD assessment in ID based on clinical notes or if communication issues caregiver provides account. Variation in PTSD presentation in those with ID makes diagnosis very difficult at current without a recognized tool. Several tools used in the case studies analyzed. <b>Application of EMDR and Acceptability:</b> All cases discuss adaptation to EMDR process to allow for ID. Story telling method used in 3 case studies. All cases demonstrated improvement in symptoms following EMDR therapy. 50% state no disturbance after treatment and substantially improved symptoms in all cases. No adverse effects. Well tolerated type of therapy. <b>Researcher Feedback:</b> Need to understand better how PTSD presents in ID individuals. Irritability/aggression, depression and low mood, and nightmares most common in these case studies. Emotional difficulties highly co morbid in ID. May be difficult to identify if emotional difficulties denote trauma symptomatology. Additional symptoms in PTSD/ID which do not fit into the traditional DSM 5 symptom criteria need to be acknowledged and collated. Great variability in the number of EMDR sessions required for each person, this may be linked to ID level. Milder cases of PTSD noted a rapid efficacy of EMDR. Need to adjust and standardize EMDR protocol for people with ID.
Limitations and conclusion:	Results:	Discussion:	Limitations and conclusion:	Comments:
<b>Limitations:</b> <ul style="list-style-type: none"><li>Summarizing of information that is not consistently documented across all case studies</li><li>Variability across case studies in terms of protocol used, method of BLS, assessment of trauma and PTSD and level of ID among clients</li><li>Authors of the literature review state that it is difficult to reliably compare the case studies due to inconsistencies in how it has been reported</li></ul> <b>Conclusions:</b> EMDR well tolerated in different levels of severity of ID. All cases reported improvements in PTSD symptoms post treatment and follow up. Sufficient evidence exists to warrant a larger scale RCT. Use of EMDR children's protocol + story telling method for lower mental ages			<ul style="list-style-type: none"><li>Excluded children from case study analysis meaning this review has extracted select information from case studies using mixtures of adults and children</li><li>Only searched for case studies, which may have limited number of hits</li><li>All case studies analyzed in this literature review were also independently assessed by this scoping review</li></ul>	

(Continued)

Table 3. (Continued).

Paper details:		Method:	Results:	Discussion:	Limitations and conclusion:	Comments:
<b>Title:</b> Is EMDR an effective treatment for people diagnosed with both intellectual disability and post-traumatic stress disorder? <b>Year:</b> 2014 <b>Country:</b> UK <b>Type:</b> Literature Review of Case Studies <b>Citation:</b> (Gilderthorp, 2015)	<b>Search Sources:</b> Four databases searched: CINAHL, ASSIA, Medline and Cochrane RCTs and Systematic Reviews Search repeated with key words found in articles collected from search. Reference search also done with two articles found this way but excluded due to no English translations available. <b>Date Ranges:</b> Search conducted with range 1987–2014. <b>Terms:</b> 9 PTSD Terms 5 ID Terms 6 EMDR Terms 5 Effect/Efficacy Terms <b>Method of Appraisal:</b> Yin's quality criteria 2009 used to critique case study designs.	<b>Exclusion:</b> Not reported <b>Literature Identified:</b> 5 pieces of literature isolated from search suitable to inclusion, all of case study design. <b>Mild ID Case Studies:</b> (Barol & Seubert, 2010; Mevisen et al., 2011a; Rodenburg et al., 2009) <b>Moderate or Severe ID Case Studies:</b> (Mevisen et al., 2011b, 2012)	<b>Clinical Salience and Control:</b> External Validity high, high clinical significance but validity and reliability of findings neglected as adequate controls not used. <b>Definitions and Outcome Measurement:</b> None of the articles in this review provide adequate information on how diagnosis of ID was made. DSM-5 criteria being met unknown. Difficulty was encountered in creating outcome measurements as a result. Range in length of follow up periods, no formal assessment criteria or outcome measurements seen, usually informal discussions with family, carers and client. <b>Role of Therapists/Carers:</b> The Mevisen publications used caregivers as co therapists which may lead to misrepresentation. By taking part in therapy caregivers might confound results by having greater insight and therefore improving their quality of care improving client's symptoms. <b>Method of BLS</b> Details of BLS not given in depth therefore cannot be replicated. <b>Ethics:</b> Issues highlighted whether consent was gained adequately from the client. The general lack of discussion of complex ethical issues in the identified articles is concerning. <b>Consideration of Alternative Explanations:</b> Considerations of alternative explanations discussed, tendency in the majority of articles to present EMDR as the sole explanation for clinical improvement without critical evaluation. Quality therefore limited according to Yin criteria.	<b>Limitations:</b> This review does not contribute to efficacy literature as no controls existed in the literature identified <b>Conclusions:</b> This review concludes that there is an ethical obligation for clinicians to provide evidence-based treatments to clients diagnosed with ID Previously thought impossible due to communication difficulties. This review suggests that this assumption is misguided Optimistic findings in this review means research with controls should take place to establish the efficacy and effectiveness of EMDR in ID Clinicians must consider closely the appropriateness of EMDR for each client and all ethical issues addressed before commencement Research implications discussed pointing toward need to develop reliable outcome measurement tools and rigorous controlled research to allow conclusions to be generalized and alter the NICE guidelines ID patients may be being denied treatment due to lack of NICE guidelines	<ul style="list-style-type: none"><li>● Including terms to narrow searches including effect/efficacy might have narrowed the number of papers available in search</li><li>● Exclusion criteria not stated for included literature</li><li>● Limited conclusions can be drawn from case study designed literature</li><li>● All articles independently reviewed in my literature search</li></ul>	

(Continued)

Table 3. (Continued).

Paper details:	Method:	Results:	Discussion:	Limitations and conclusion:	Comments:
<p><b>Title:</b> PTSD and its treatment in people with intellectual disabilities: a review of the literature</p> <p><b>Year:</b> 2010</p> <p><b>Country:</b> Netherlands</p> <p><b>Type:</b> Literature Review</p> <p><b>Authors:</b> (Mevissen &amp; De Jongh, 2010)</p>	<p><b>Search Sources:</b> Five sources used: Picarta citations, PubMed journal citations, National Association for the Dual Diagnosed bulletins, Book chapters and Book references. Search of references section of each article for relevant titles was performed.</p> <p><b>Date Ranges:</b> Search conducted with range 1992–2008.</p> <p><b>Terms:</b> Post-traumatic stress disorder, trauma, life events, anxiety disorders, psychiatric disorders, mental health problems, intellectual disability, mental retardation, learning disability, assessment, diagnostic instruments, prevalence, treatment and psychotherapy.</p> <p>Search terms used in combination with descriptive labels.</p> <p><b>Method of Appraisal:</b> Studies analyzed for three topic areas: assessment of PTSD in people with ID, Prevalence of PTSD in people with ID, and treatment of PTSD in people with ID.</p>	<p><b>Exclusion:</b> No exclusion criteria applied</p> <p><b>Literature Identified:</b> 18 studies identified and reviewed of which 2 were relevant to this scoping review: (Gitlaj, 2004; Tharner, 2006)</p>	<p>(Gitlaj, 2004):</p> <p><b>Demographics:</b> Total Number of Participants (n = 2) <b>Participant 1</b> – Female of unknown age <b>ID Severity</b> – Mild ID <b>Neurodevelopmental or Autism</b> – Not reported <b>Level of Verbal Communication</b> – Not reported <b>Comorbidity</b> – Not reported <b>Medication</b> – Not reported <b>Participant 2</b> – 16-year-old Female <b>ID Severity</b> – Not reported <b>Neurodevelopmental or Autism</b> – Not reported <b>Level of Verbal Communication</b> – Not reported <b>Comorbidity</b> – Visually impaired <b>Medication</b> – Unknown <b>Data Collection:</b> Case notes <b>Responsible Person for PTSD/ID Diagnosis:</b> Not reported <b>Criteria used to diagnose PTSD/ID:</b> Not reported <b>EMDR Protocol:</b> Detailed protocol described with adaptations to cognitive and visual impairments</p> <p><b>Outcomes:</b> <b>Primary Outcome:</b> Subjective feedback from participant and Likert scale symptoms severity measurement <b>Participant 1:</b> 4 sets of EMDR therapy before PTSD symptoms disappeared, results maintained at 3 months follow up <b>Participant 2:</b> Problem severity Likert scale scores reduced from 9/10 pretherapy to 1/10 posttherapy (Tharner, 2006):</p> <p><b>Demographics:</b> Total Number of Participants (n = 20) <b>ID Severity</b> – Mild <b>Neurodevelopmental or Autism</b> – Not reported <b>Level of Verbal Communication</b> – Not reported <b>Comorbidity</b> – Not reported <b>Medication</b> – Not reported <b>Data Collection:</b> Not reported <b>Responsible Person for PTSD/ID Diagnosis:</b> Not reported <b>Criteria used to diagnose PTSD/ID:</b> Not reported <b>EMDR Protocol:</b> Not reported</p> <p><b>Outcomes:</b> <b>Primary Outcome</b> – Not reported <b>Results</b> – 80% of sample successfully treated. At the end of treatment participants were able to think of traumatic event without any disturbance and the validity of newly formulated positive cognition felt to be highly true.</p>	<p><b>Limitations:</b></p> <ul style="list-style-type: none"><li>● Much information missing on diagnostic criteria in both studies</li><li>● details of EMDR and outcome measures</li><li>● No information presented on how PTSD was diagnosed and how results were measured</li><li>● Unclear how problem severity scale was used in each domain, just states genetic decrease</li><li>● No information on validity of problem severity scale</li><li>● No definition of what disappearance of PTSD symptoms meant</li><li>● Follow up data lacking and definition of results remaining after 3 months not clear</li><li>● Used search beginning in 1992, but concept of EMDR was coined in 1987 meaning literature could have been missed</li><li>● Search terms used not specific to PTSD as stated as the focus in this literature review</li><li>● No systematic way of gathering information used</li><li>● No specific exclusion criteria used</li><li>● <b>Conclusions:</b> Poor or no information offered on how PTSD was diagnosed</li><li>● Case reports suggest positive treatment effects, but PTSD treatment in people with ID has proven to be relatively complicated and is in its infancy</li></ul>	<ul style="list-style-type: none"><li>● Full article not used, only the results referring to EMDR</li><li>● Literature review describes two case reviews</li><li>● Very limited use of this as much information is missing</li><li>● Very general search done on all types of therapies to combat PTSD in ID including CBT and other psychotherapeutic approaches</li><li>● The two articles reviewed in this literature review were not included in this scoping review as they were not available in English</li><li>● Summaries of the studies as detailed in Mevissen and De Jongh (2010) are given in this table entry</li></ul>

which a PhD thesis), one mixed methods RCT and one qualitative multiple baseline case series. Tables 1–3 summarize the findings of this review.

## DISCUSSION

### *Previous Literature Reviews*

This scoping review identified three literature reviews which attempt to evaluate the use of EMDR in people with ID (Gilderthorp, 2015; Jowett et al., 2016; Mevissen & De Jongh, 2010). All publications identified in the literature reviews published by Jowett et al. in 2016 and Gilderthorp in 2015 appeared in the search results for this scoping review, who identified six and five publications, respectively. All of these publications were of case study or case series design. The Mevissen and De Jongh (2010) literature review described two studies concerning the use of EMDR in people with ID, which the authors of this scoping review were unable to access due to lack of availability in English (Giltaij, 2004; Tharner, 2006). These two studies are summarized in Tables 1 and 2, the details of which gathered from descriptions given in the Mevissen and De Jongh (2010) publication. Omitting the three literature review publications identified by this scoping review, we captured 13 pieces of literature which attempt to assess the efficacy of EMDR in people with ID. Gilderthorp in 2015 and Jowett, et al. in 2016 attempted to discuss similar content to the authors in this scoping review, whilst Mevissen and De Jongh in 2010 took a much broader approach by discussing multiple therapy types to combat PTSD in people with ID.

### *Important Findings*

The majority of publications analyzed in this scoping review demonstrate positive results, indicating that EMDR may be highly efficacious in people with ID. However, the more recent publications in this scoping review suggest some less favorable results. The only RCT yielded from this scoping review suggested that whilst EMDR produced improvements in PTSD symptoms, it was not significantly more effective at improving symptoms compared to standard therapy (Karatzias et al., 2019). Participants were assigned to an EMDR therapy with standard care group (EMDR + SC), and a standard care only group (SC Only). In EMDR + SC, seven patients were PTSD diagnosis free at follow up, whilst in SC Only, four patients at follow up were PTSD diagnosis free. Analysis revealed no statistical significance between the two results suggesting equal efficacy. However, given the small sample size, there is high likelihood of a type 2 error complicating the ability to draw reliable conclusions.

Qualitative research based on interviews with participants undergoing EMDR and their therapists suggested that EMDR was not well tolerated (Unwin et al., 2019). Themes arose highlighting that EMDR was disruptive to the therapeutic alliance between participant and therapist. EMDR was also said to be too technical a process with little room for adaptation and flexibility. Furthermore, too much focus was placed on the past with little relevance to events occurring between therapy sessions. There was also cautious optimism that EMDR may be useful only in particular patients at the correct time. All patients that started on EMDR in this study reverted back to their usual way of therapy, suggesting it was not well tolerated.

One book also discussed EMDR and the cultural construction of ID, describing a severe adverse reaction to the treatment in one of the author's patients (Yaskin & Seubert, 2017). After two brief sets of bilateral stimulation, the patient fled the treatment room and attempted to hurl themselves in front of a car.

The three literature reviews published between 2010 to 2016 were not able to capture these results, allowing this scoping review to summarize new evidence which contrasts more positive popular opinion (Gilderthorp, 2015; Jowett et al., 2016; Mevissen & De Jongh, 2010). This raises questions over the reliability of positive findings. Perhaps a lack of published less efficacious findings favors the use of EMDR in people with ID, skewing the view on its efficacy. In conjunction, all studies have significant limitations and inconsistencies in design that hinder the generalizability and applicability of results.

### ***Heterogeneity of Population Characteristics***

One major issue raised by the authors of this scoping review concerns the heterogeneity of participants. The literature identified from this scoping review involved participants with varying combinations of ID severity, verbal articulation, psychotropic drug prescription and autism diagnosis. Comparing different studies with heterogeneous samples, as well as drawing conclusions from individual studies with high levels of heterogeneity, may confound results and complicate the evaluation of efficacy.

With regards to having a diagnosis of autism, amongst these individuals exists neurodiversity as a result of cognitive distortion. This means that autistic individuals may present as though they have a cognitive deficit, as is present in individuals with ID, but in fact do not have a true reduction in intelligent quotient (Hurley & Levitas, 2007). As long as information given to these individuals is communicated in an acceptable format that suits their needs, they can be included in mainstream EMDR therapy without the adaptations necessary for those with a cognitive deficit. To complicate matters, a significant proportion of individuals are comorbid with both ID and autism (Hurley & Levitas, 2007). With respect to the articles included in this scoping



review, those that used mixed autistic and non-autistic samples may have confounded their results as true cognitive deficit may not be present. Autism along with the other aforementioned confounding factors compromises the ability of the analyzed articles to test the efficacy of EMDR in individuals with ID.

Looking at the literature identified in this review, a PhD thesis described a multiple baseline across participants study with a very low level of heterogeneity (Buhler, 2014). Participants were all verbally articulate, non-autistic, and diagnosed with mild ID using the Wechsler abbreviated scale. In contrast, a case series published in 2010 displayed high levels of heterogeneity, where participants had varying levels of verbal articulation, a mixture of autistic and non-autistic diagnoses, and varying severities of ID (Barol & Seubert, 2010). Less confounding factors exist in the first publication, meaning the reduction in PTSD symptoms are better controlled and more likely to be due to EMDR therapy. It is crucial for future research to homogenize populations, reducing the number of confounding factors and allowing better comparison of literature.

### ***EMDR Protocol and Its Adaptations***

The authors of this scoping review identified a range of methods used to administer EMDR, but with all identified literature using methods derived from the most up-to-date version of the Shapiro Adult and Child protocols available at the time (Shapiro, 2017). Various adaptations were made to these processes to suit the needs of the client, one such being the method of BLS. It was quite frequently reported that participants tended to tolerate eye movements less well than other forms of BLS. Alternative BLS used were tactile or auditory in nature, using hand buzzers, knee tapping, speakers and headphones. Authors of the literature identified from the scoping review commonly reported participants having difficulty understanding the abstract concept of validity of cognition (VOC) and subjective units of distress (SUD) scales, which often required adaptation. Pointing to visual cues with facial expressions and hand spreading were common methods of portraying experienced emotions and quantifying the level of emotional distress, bypassing issues with SUD and VOC scales. These methods are known to have been effective in previous literature (Adler-Tapia & Settle, 2008; Greenwald, 1999). The authors of the 2010 case series proposed that a longer preparation phase was required to help build the therapeutic relationship between client and participant compared to adult counterparts without ID (Barol & Seubert, 2010). More frequent SUD checking was also done to monitor changes in emotional distress, with disturbing memories broken down into smaller more manageable chunks to aid understanding and processing. In several studies, a story telling method was employed as a better way of enabling the client to

communicate and follow their thoughts surrounding disturbing memories (Mevisen et al., 2011a, 2011b, 2012). This is a method developed by Joan Lovett and detailed in her book publication (Lovett, 1999). The 2012 case series by Mevisen et al. interestingly used noises, smells, objects and physical sensations related to the client's disturbing memory as a way of enhancing recollection of the experience when verbally discussing the memory was not sufficient.

The Dilly (2014), and Seubert (2005) publications did not give detailed information on EMDR protocol. This highlights the need for future research to specify protocol to allow replication of research, a point mentioned in a 2015 literature review (Gilderthorp, 2015). Furthermore, the noticeable difference in protocols and adaptations used between studies is highly variable and further complicates the ability to evaluate efficacy. Consensus must be reached on which methods have the greatest chance of success in future research. Simultaneously, different protocols may be more successful in different patient subgroups, something which must be explored further.

### *The Assessment of Trauma and PTSD in ID*

Assessing emotional trauma and PTSD is difficult in patients with ID due to difficulties in communication during clinical interviews, and lack of rigorously tested PTSD and trauma assessment tools specific to people with ID. These tools are used to assess whether an individual has signs, symptoms and sufficient quantitative test measures to warrant a diagnosis according to the definition of PTSD as defined by the most up-to-date version of the diagnostic and statistical manual of mental disorders (DSM). The authors of literature identified from this scoping review used a variety of methods to assess emotional trauma and PTSD symptoms. All of the Mevisen case series demonstrate a more subjective approach to trauma assessment and PTSD diagnosis (Mevisen et al., 2011a, 2011b, 2012). Clinical interview was used to determine if a participant met the criteria for PTSD as set out in the DSM, after which subjective feedback from participants and accompanying carers was used to measure change in symptoms. No objective quantitative measures were used to monitor symptom progression, complicating the evaluation of efficacy. Patients may have been misrepresented by caregivers who often speak on behalf of the participant, confounding the true progress of the patient. Barol and Seubert in 2010 used a bespoke assessment tool for PTSD, created using a combination of the DSM 19 symptom checklist, 59 item psychiatric questionnaire, Sovner (1993) adaptive checklist of psychiatric symptoms and a generic 32-item list of indicators of PTSD in people with ID. Pre and post therapy evaluations using the bespoke assessment tool assessed change in PTSD symptoms. This bespoke tool was not reliably tested in a population with ID, which may have confounded the results. Three

publications used versions of the impact event scale (IES) to measure changes in PTSD symptoms, with the Buhler publication in 2014 also evaluating changes using the C-PTSD-I scale (Barrowcliff & Evans, 2015; Buhler, 2014; Rodenburg et al., 2009). Other measures used include the PCL-5, Life Events Checklist, Childhood Trauma Questionnaire and Posttraumatic Diagnostic Scale.

One notable tool used by Mevissen et al. in 2017 was the ADIS-C-PTSD, a trauma and PTSD assessment tool devised specifically for use in children with ID. This was the only scale used in the literature tailored specifically for use in people with ID. The assessment tool consists of a series of "yes" or "no" answer questions combined with an interview using simplified language and visual cues to determine a PTSD diagnosis. In 2020, Mevissen et al. proposed an adult version of this assessment tool and tested its suitability in adults with mild ID. The study found the ADIS-C-PTSD-adult to be suitable for use in this population and a valid assessment tool. In 2019 a literature review identified three PTSD assessment tools for use in people with ID (Daveney et al., 2019). These tools included the child version of the ADIS-C-PTSD, the Lancaster and Northgate Trauma Scale and the Impact of Event Scale – Intellectual Disabilities (Wigham & Emerson, 2015; Wigham et al., 2011) The authors suggest that the currently available tools must be compared and assessed for acceptability and efficacy to help improve PTSD diagnosis in ID.

The number of assessment tools used in the literature is overwhelming and questions the best way to assess PTSD and trauma symptoms in people with ID. Several tools at present exist for use in people with ID, but consensus does not yet exist. A universally accepted and reliable way of assessment must be developed and tested in the target population to aid future research.

### *Limitations of This Review*

Despite a robust attempt to capture all relevant literature, some articles were unable to be included due to language barriers, lack of access and lack of detailed information to be able to draw valuable conclusions. Some articles also may not have been identified using the terms defined in [Appendix B](#), and so other terms may exist. Both of these factors have limited the potential breadth of literature available for this review. Due to the inclusive nature of a scoping review, non-peer-reviewed articles and literature with a low GRADE score were included, which tended to be of GRADE score 4 or below. These factors complicate the ability to reliably assess the efficacy of EMDR in people with ID. Furthermore, the method of reporting studies was not always consistent for each piece of literature, making direct comparison more complicated.

## CONCLUSION

### *Implications for Research*

Research over the last 20 years suggests that EMDR may be an effective treatment for emotional trauma and PTSD in an intellectually disabled population of individuals. However, more recent findings suggest EMDR may be less efficacious in individuals with ID than previously thought, with some older publications suggesting adverse events to the therapy. Many issues in population characteristics, and study design exist in the current literature, complicating the ability to evaluate efficacy. Future research should focus on generating a reliable EMDR protocol suitable for use in people with ID as well as a reliably tested emotional trauma and PTSD assessment tool. Following this, RCTs need to be performed using homogenized populations to determine the efficacy of EMDR in people with ID.

### *Implications for Clinical Practice*

At present, there is not yet a sufficient literature base on which to reliably conclude that EMDR therapy is efficacious in people with ID. Better designed research in the future will generate results which can be used to more reliably compare literature. By doing this, a more solid evidence base can be created, helping build the foundations to generate a more inclusive NICE guideline for EMDR use.

## DISCLOSURE STATEMENT

No potential conflict of interest was reported by the author(s).

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## Appendix A. Summary of EMDR therapy

EMDR is an eight-phase psychotherapy developed by Francine Shapiro in 1989, used primarily to treat post-traumatic stress disorder (PTSD) and less frequently other psychiatric conditions (Shapiro, 2017). Initially a period of assessment identifies the details of underlying emotional trauma and maladaptive behavioral and psychosomatic symptoms in response to this trauma. The patient is then guided by the therapist through memories of this trauma whilst bilateral stimulation (BLS) is administered, usually in the form of eye movements. Other forms



of BLS using auditory and tactile methods have also been shown to be effective (Shapiro, 2017). The combination of stimulation and traumatic memory recall desensitizes the patient, reducing the intensity of the distressing responses. Distress level is measured using subjective units of distress (SUD), a scale used to quantify distress during traumatic memory recall. Maladaptive responses are said to be eliminated once SUD scores reach zero. An installation phase helps associate positive cognitions with traumatic memories to prevent distressing maladaptive responses. The validity of cognition (VOC) scale is used to measure whether this positive cognition is truly believed by the patient.

## Appendix B. Terms used in search methodology

### *Eye Movement Desensitization Reprocessing*

exp "EYE MOVEMENT DESENSITIZATION REPROCESSING"/  
(EMDR).ti,ab

(eye movement desensiti?ation).ti,ab

### *Intellectual Disability and Autism*

(autism OR autistic).ti,ab

(asperger\*).ti,ab

(kanner OR kanners OR rett OR retts).ti,ab

("pervasive development\* disorder\*").ti,ab

"LEARNING DISORDERS"/

exp "CHILD DEVELOPMENT DISORDERS, PERVASIVE"/OR "RETT SYNDROME"/

"non-verbal learning disorder\*" OR "non-verbal learning disabilit\*" OR "nonverbal learning disorder\*" OR "nonverbal learning disabilit\*".ti,ab

(nonverbal OR non-verbal).ti,ab

(nld).ti,ab

("learning disabilit\*").ti,ab

(mental\* OR intellect\* OR development\*) ADJ (deficien\* OR disabilit\* OR disabled OR retard\* OR handicap\* OR impair\*).ti,ab

(intellect\* OR mental) ADJ development\*

("cognitive retardation" OR "dull intelligence" OR "low intelligence").ti,ab

("mental deficit").ti,ab

("intellectual deficit").ti,ab

exp "INTELLECTUAL DISABILITY"